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EDITORIAL

Towards best practice: Urgent need for surrogacy birth care guidelines in Australia

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Surrogacy, defined as the process in which a woman* carries and delivers a child for intended parents (IPs), has become an increasingly popular path to parenthood in Australia. Recent estimates suggest that there are around 130-150 surrogacy births occurring annually; a number that has nearly doubled over the last decade.[1] Despite the rising demand for surrogacy, especially among individuals and couples facing infertility or who are gender and sexually diverse, the healthcare system in Australia is not adequately prepared to manage the unique challenges associated with surrogacy birth care.[2] In contrast to countries such as the United Kingdom, where the Department of Health & Social Care has established guidance to support healthcare professionals in the care of surrogates and IP during surrogacy births,[3] Australia currently lacks cohesive, evidence-based policies to guide surrogacy birth practices. This deficiency in policy results in inconsistent care, thereby posing serious health, safety, and emotional risks for surrogates, IPs, and the newborns involved.[2,6]

Healthcare professionals, especially nurses and midwives, are at the forefront of managing pregnancy and surrogacy births. However, they often encounter uncertainties and challenges due to the lack of clear protocols.[4,5] Without a structured approach, the care provided can become inconsistent and misaligned with the needs of surrogates, IPs, and babies.[5-7] This inconsistency not only leads to disparities in treatment but also imposes unnecessary emotional and psychological burdens on surrogates and IPs.[6,8]

Despite good intentions, many healthcare professionals have a limited understanding of surrogacy arrangements and the roles of IPs.[8] As a result, IPs may be excluded from delivery rooms or other critical post-birth activities, such as skin-to-skin contact, catching their baby for the first time, or cutting the umbilical cord.[6,9] This exclusion can disrupt early parent-child bonding and leave IPs feeling marginalised during the initial stages of their child's life, even though research suggests that the involvement of IPs during delivery and the immediate post-birth period is crucial for their emotional well-being and fostering parental bonds.[10] Conversely, surrogates may feel pressured into activities that they had not anticipated or might be unwilling to participate in, such as breastfeeding or extended hospital stays, due to the healthcare team's limited understanding of the unique dynamics of surrogacy care.[6] Evidence also indicates that some surrogates in Australia have been denied access to delivery services because hospitals lack specific surrogacy care policies, and healthcare professionals often do not recognise surrogacy arrangements as legal, despite altruistic surrogacy being made legal at different times in each state and territory.[9,11] In some instances, surrogates have even been

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*We acknowledge that not everyone who carries and delivers a child will identify as a woman.

refused discharge from the hospital unless they left with the baby, and IPs have been either ignored by staff or not accepted as the child's parents.[9]

In such situations of surrogacy care, nurses and midwives, as primary providers of care, often find themselves navigating a delicate balance between the principles of woman-centred care and the unique needs of surrogacy arrangements. The values and principles of Women-centred care emphasise safety, respect, choice and equitable access to care.[12] However, in the context of surrogacy, nurses and midwives must also consider the involvement and expectations of IPs while balancing the autonomy of surrogates – often without sufficient guidance on how to manage these dual responsibilities effectively.[5,7] This creates a challenging situation for nurses and midwives who genuinely want to provide appropriate care but may feel uncertain about how to meet the needs of both the surrogate and the IPs. Such situations not only cause emotional distress for all parties involved but can also strain relationships and contribute to long-term psychological impacts.[13,14] These challenges can also erode trust between surrogates, IPs, and healthcare providers, leading to enduring consequences for future interactions with the healthcare system.[8,15]

The lack of standardised guidelines to support healthcare professionals in navigating these sensitive interactions and the unique dynamics of surrogacy birth care is a significant issue particularly as surrogate parenthood is likely to become more common. Without clear directives, healthcare professionals may face dilemmas about whose interests to prioritise – those of the surrogate, the IPs, or the child – leading to challenges in managing the complex nature of both birth and surrogacy care. This lack of clarity can result in disputes and confusion, further complicating an already delicate process.

To address these critical gaps, the development of comprehensive, evidence-based practice for surrogacy birth care is essential. Such guidelines would provide a unified approach, offering healthcare professionals the tools and protocols necessary to manage surrogacy cases confidently and compassionately. Clear guidelines would help define the roles and responsibilities of healthcare professionals, ensuring appropriate care for surrogates and IPs at each stage of antenatal, delivery and post-delivery, thereby informing and supporting everyone throughout the journey. By incorporating insights from research and best practices, these guidelines could standardise care practices, promoting equitable treatment for all involved.

A surrogacy birth care framework would also enable the integration of specialised training programs for healthcare professionals, enhancing their understanding of the complexities inherent in surrogacy care. Such training would foster a more supportive and empathetic approach, reducing biases and enhancing the overall quality of care provided to surrogacy cases.[7] Additionally, guidelines would serve as a reference point for managing challenging scenarios, such as determining the appropriate level of IP involvement during delivery and effectively addressing the needs of both surrogates and IPs in caring for the surrogate-born baby.

The current lack of standardisation in surrogacy birth care practices in Australia underscores the urgent need for action. As surrogacy arrangements continue to rise, the healthcare system must evolve to meet the unique needs of surrogates, IPs, and their newborns. By developing and implementing evidence-based guidelines for surrogacy birth care, Australia can set a new benchmark, ensuring healthcare professionals have the tools and guidance to improve the quality and consistency of care. This will support the delivery of safe, effective, and optimised care, promoting the best possible outcomes for all parties involved.

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RESEARCH ARTICLES

'One size does not fit all': Nurses' and midwives' opinions about using electronic medical records

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ABSTRACT

Objective: To describe the impact that electronic medical record (EMR) documentation has on nurses' and midwives' practice.

Background: Although both advantages and disadvantages of a digitised health system have been documented, nurses and midwives continue to express concerns about the effect EMRs and computers have on their practice and patient relationships.

Study design and methods: A cross-sectional survey design was used. An anonymous questionnaire was distributed in electronic and paper formats to identify nurses' and midwives' opinions of the impact of EMRs and computers on their practice and patient relationships in a regional tertiary-level hospital. Quantitative data was analysed descriptively; free-text responses were analysed thematically.

Results: Nurses ($n = 31$) and midwives ($n = 49$) responded. Both respondent groups disagreed that the EMR had improved teamwork with other health professionals. Overwhelmingly, midwives disagreed that EMRs had improved the quality of care ($n = 43$, 87.8%). Nurses agreed EMRs had improved documentation standards ($n = 24$, 77.4%) and patient safety ($n = 22$, 71%). However, midwives responded that EMRs had not improved women's safety ($n = 31$, 63%). Three themes emerged from the data: computers affect my productivity; computers affect my relationship with the patient/woman; the EMR increases my frustration and stress levels. Nurses and midwives felt the heavy documentation load and lack of integration across the EMR platform reduced efficiency, discouraged teamwork, and further excluded patients/women from participating in their care.

Discussion: Although nurses and midwives agreed that the accessibility of EMRs to all health care staff is advantageous, the documentation demands of each clinical area are vastly different. The hybrid system of paper and electronic documentation increases documentation workload. Generally, midwives were more critical of the impact of EMRs on their practice.

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Conclusion: Nurses and midwives identified current challenges of EMRs with respect to productivity, relationships with patients and colleagues, and user wellbeing aligning with results of other published studies. As primary users of EMRs, nurses and midwives can offer valuable feedback to health services to help deliver digitised healthcare that is user-friendly, and patient/woman centred.

Implications for research, policy, and practice: Organisations need to enact policies and procedures that facilitate nurses and midwives identifying areas of potential improvement to increase the usability and operability of the EMR. Such processes should lessen the negative impacts of EMR (such as documentation burden) on nursing/midwifery practice, with the aim of enhancing clinical and safety outcomes. It is suggested that ethnographic research studies be undertaken to gain a deeper understanding of the EMRs on nurse/midwife productivity, wellbeing, job satisfaction and patient safety concerns.

Keywords: Attitude to Computers; Electronic Health Records; Cardiovascular Nursing; Midwifery; Nursing; User-Centered Design.

What is already known about the topic:

- Positive and negative EMR outcomes for patients and clinicians have been documented.
- Involving clinicians (especially nurses and midwives) in the development of digital systems prior to implementation has been shown to reduce negative attitudes towards them.
- Ongoing user analysis is recommended in human-centred design to improve usability and user wellbeing.

What this paper adds:

- Description of the differing experiences and challenges faced by nurses and midwives using the EMR program and computers in the same hospital.
- Positive and negative effects of the current EMR program and computers have been identified.
- This paper verifies the results of other national studies about the effects of EMRs and computers on nurses' and midwives' productivity, relationships, and wellbeing.

OBJECTIVES

The objective of this study was to describe the impact that electronic medical record (EMR) documentation has on the practice of nurses and midwives.

BACKGROUND

Digitalised medical information is transforming healthcare. Nurses and midwives are at the forefront of patient care and are the primary users of EMRs. Whilst nurses and midwives have the skills and knowledge to adapt to complex systems,[1] it is reported that nurses feel negatively towards using EMR due to the difficulty of use and irrelevance to meaningful patient care.[2] Debono et al. suggest that nurses do not always use electronic documentation systems because such systems require them to adapt their usual routines and behaviours.[3] For example, because of either clutter or infection risks, nurses may not take a computer into the patient's room when administering medication, meaning that documentation of medication administration occurs away from the patient. Mysen, Penprase and Piscotty advise that nurses and midwives must be able to use technology without sacrificing patient/woman care relationships and interactions to improve client satisfaction.[4]

Nurses not only provide direct patient care but also serve as 'knowledge workers', managing vast amounts of data daily. Nurses utilise EMRs to create a comprehensive patient narrative that can enhance the quality and safety of care they deliver.[5,6] While it is reported that EMRs have the potential to streamline and automate processes, increase time to focus on direct care, improve patient outcomes and experiences of care, some nurses are struggling to see the benefits and efficiencies of EMR as patient care shifts towards technology and away from the bedside.[7,8]

Research is divided as to the impact of digital health systems on nurses' workload. Some studies conclude that digital health systems improve nurses' efficiency,[9,10] or make little difference.[11] However, other studies have identified documentation in EMRs as a major contributor to significantly increasing nurses' workloads.[12-15]

In the public health system in Queensland, Australia, there has been an investment in digital hospitals with the progressive rollout of EMRs across the state. Following a trial at a large public hospital in Queensland, there was a multi-phase rollout of the integrated electronic medical record (ieMR, Cerner) at Townsville University Hospital from 2015, taking the hospital from a paper-based system to a digital system. Whilst the EMR platform has been used in the hospital since then, nurses and midwives anecdotally report they face multiple challenges associated with the EMR. For instance, the capabilities of the EMR vary across the hospital as many specialised areas require specialised documentation that have not yet been digitised due to financial or technical constraints. This means that the EMR is constantly changing across the health service with new capabilities being rolled out frequently. In some clinical situations (e.g. monitoring a patient post-angiogram), paper-based systems may still be required and later uploaded to the EMR. If there are physical restrictions (e.g. room size) or technical limitations (e.g. battery failure) which prevent the use of mobile workstations, nurses will utilise fixed workstations where available.

Given the small number of studies that have explored the perspectives of nurses and midwives towards EMRs, this study addressed this gap in evidence by describing the collective perspectives of both nurses and midwives about the EMR and how EMRs have impacted their practice.

METHODS

STUDY DESIGN

A cross-sectional survey design was used. An anonymous questionnaire was developed to identify nurses' and midwives' opinions of EMRs and computers in nurse/midwife practice. This design aimed to ascertain whether nursing and midwifery practice is impacted by EMRs and provide further understanding of how technology can influence their productivity, relationships, and wellbeing.

Setting

This study was conducted in the Cardiac Centre and the Maternity Service within the largest tertiary hospital in Northern Australia. The Cardiac Centre includes the Cardiac Ward and Coronary Care Unit. The Maternity service includes the Antenatal Clinic, Maternity Ward, Birth Suite and Birth Centre.

Participants

All nurses (approximately 80) employed in clinical positions in the Cardiac Centre at the time of survey distribution (September 2021) were invited to participate. Agency and student nurses were excluded.

All midwives (approximately 120) employed in clinical positions at the time of survey distribution (April 2020) were invited to participate. Agency and student midwives were excluded.

Questionnaire tool

At the time of designing the study, we could not find a validated questionnaire that addressed our area of interest. Thus, the questionnaire items were developed from a review of the literature, piloted for face validity, and offered in both electronic and paper formats. The anonymous questionnaire took approximately 10 minutes to complete. There were four sections to the questionnaire. Section A was comprised of statements about using the EMR and its impact on nursing/midwifery practice. An example statement was: "Use of the EMR improves the efficiency of nursing/midwifery care". Section B comprised statements about the impact of the EMR on their nursing/midwifery practice, and Section C comprised statements about perceptions of patients'/women's experience of the EMR. Participants were asked to respond to statements in each of these three sections using a five-point Likert scale of agreement. Table 1 lists the statements from these three sections. Section D asked questions about respondents' nursing/midwifery practice and professional development. The questions asked about: years of practice; employment (full-time, part-time, or casual): methods of documentation (electronic and/or paper); where they access the EMR (fixed workstation and/or mobile workstation); whether the initial training and ongoing support to use the EMR met their needs. There were several free-text questions in the questionnaire, which asked for comments about the impact of the EMR on nursing/midwifery in general and on their nursing/midwifery practice, any perceptions of the impact of the EMR on patients'/women's experience of care, and any suggestions they had for improving the EMR. It is from these responses that the themes were developed. Slight changes were made to the number and wording of the statements/questions when the tool was modified for use in the cardiac setting.

Questionnaire distribution

Potential participants were informed about the research via email, flyers, and staff meetings. Researchers took paper copies to each area along with a box in which to place completed paper questionnaires. Nurses and midwives were also informed about the option of completing the questionnaire electronically, via the Qualtrics platform, by following a link in the email or a QR code. The data collection period for each group was four weeks; reminder emails were sent at two weeks.

Ethical considerations

The study was approved by the Hospital and Health Service Human Research Ethics Committee (HREC/QTHS/71848). A Participant Information Sheet was attached to the paper questionnaires; consent was implied by placing a completed questionnaire in the collection box provided. For the electronic format, the Participant Information Sheet was inserted as a landing page to the questionnaire. Participants consented by checking that they agreed to participate in the study and questionnaire logic progressed the participant to the items. If they did not agree, they were diverted to a "thank you" message and exited the questionnaire.

DATA ANALYSIS

Responses to the online questionnaire were downloaded from the Qualtrics software and merged with the responses from paper questionnaires, that had been manually entered into an Excel spreadsheet. Each set of questionnaire data was then assigned a unique participant number (N01-N31, M01-M49).

For data analysis, the original response categories to the five-point Likert-scale questions were collapsed into three categories. The original response categories of 'strongly agree' and 'agree' were collapsed to form the new response of 'Agree'. Similarly, the original response categories of 'disagree' and 'strongly disagree' were collapsed to form the new response of 'Disagree'. Data were summarised descriptively using SPSS Version 28 (IBM Corp. 2021).

Open-text responses were analysed thematically, guided by the framework of Braun and Clarke.[16] This framework has six stages: becoming familiar with the data; generating initial codes; searching for themes; reviewing themes; defining the themes; and producing a report of the analysis. Firstly, responses to all free-text questions were collated and entered into an Excel spreadsheet, from which two researchers independently familiarised themselves with the text and developed initial sub-themes. The researchers then conferred to visually map their notes to identify patterns across the sub-themes and develop tentative themes. A brainstorming meeting was held to discuss these and refine the final set of themes.

RESULTS

RESPONSE RATE

Thirty-one nurses (31/80, 39%) and 49 midwives (49/120, 41%) responded. Twenty-one nurses and 36 midwives completed the paper version of the questionnaire.

PROFESSIONAL DATA – NURSES

Twenty-eight of the nurses indicated their years of nursing experience. This ranged from 1 to 41 years, median$n=10.0$ years (IQR 16.25). The majority worked part-time ($n=20/31$, 64.5%), with the remainder ($n=11/31$, 35.5%) working full-time. Four (12.9%) nurses said they exclusively used electronic documentation, whereas the remaining 27 (87.1%) documented on a combination of paper and electronic. Eleven (35.5%) used the EMR on a mobile workstation, and the remainder ($n=20$, 64.5%) used the EMR on both mobile and fixed workstations.

PROFESSIONAL DATA – MIDWIVES

Most midwives primarily worked in the inpatient maternity ward ($n=33/48$, 68.8%) with the remainder in Birth Suite ($n=6/48$, 12.5%), antenatal clinics ($n=5/48$, 10.4%), or care models providing both antenatal and birthing care ($n=4/48$, 8.3%). Midwife respondents had been practicing midwifery between 1 and 36 years, median$n=8.5$ years (IQR 15.75). Half indicated they worked full-time ($n=23/46$, 50%), with the remainder working part-time ($n=22/46$, 47.8%) or casually ($n=1/46$, 2.2%). Midwives documented on a combination of workstations (fixed or mobile), laptops or on paper, depending upon their area of practice at any given time.

EXPERIENCES OF USING EMR

Nurses and midwives were asked about their agreement with statements related to their experiences of using the EMR. There were differences in the level of agreement across some questions by disciplines (Table 1). For example, the nurse respondents were more positive about the EMR improving the safety of care than the midwife respondents. No midwife respondents agreed that the EMR improved the quality of care they provided. Approximately one-quarter of nurses and midwives agreed that the EMR improved efficiency of their care. Whilst approximately half of the nurses and midwives agreed that the initial training about the EMR met their needs, fewer midwives agreed that their ongoing training needs were being met.

INITIAL AND ONGOING TRAINING ABOUT EMR

There were no statistically significant relationships between mode of work (full/part time) and agreeance whether either the initial, or the ongoing, training to use the EMR met midwife respondents' needs ($\chi^2=0.782$, $p=0.376$; $\chi^2=0.297$, $p=0.586$ respectively). The assumptions for undertaking other chi-square analyses of relationships between nurses' and midwives' professional characteristics and agreeance whether either the initial or ongoing training to use the EMR met their needs were not met.[17]

FREE-TEXT RESPONSES

Three themes were developed from the free-text responses: "Computers affect my productivity"; "Computers affect my relationship with the patient/woman"; and "EMRs increase my frustration and stress". Themes, sub-themes and illustrative comments are presented in Table 2.

Theme 1: Computers affect my productivity

There were positive comments about the potential of EMRs to improve communication amongst the multidisciplinary team, and the ability for multiple health professionals to document in the chart simultaneously. For example, one nurse with 8 years' experience wrote that "It does make it easier that all teams and nurses can document at the same time" (N01); another nurse with 20 years' experience agreed that the EMR "is good for the clinician having all the available information quickly" (N04). However, negative comments were more common (refer to Table 2). One nurse, with 8 years' experience, shared concerns that the administration of newly prescribed medications in the EMR could be delayed, because the system provided no alerts to a new medication being prescribed (N01). The nurse (N01) suggested a pop-up box alerting them to changes in the patient's medication orders would be ideal to prevent delayed medication administration and would bridge this gap in communication between doctors and nurses.

TABLE 1: USING THE EMR: NURSES' AND MIDWIVES' AGREEMENT WITH STATEMENTS ABOUT THEIR EXPERIENCES

		Nurses' responses (*N* = 31)[a]			Midwives' responses (*N* = 49)[b,c,d,e]		
		Agree	Neutral	Disagree	Agree	Neutral	Disagree
Section A: Experience of using the EMR and its impact on nursing/midwifery practice in general							
1	Use of the EMR improves the overall safety of nursing/ midwifery care	22 (71%)	3 (9.7%)	6 (19.4%)	8 (16.3%)	10 (20.4%)	31 (63.3%)
2	Use of the EMR reduces the likelihood of drug errors	18 (58.1%)	4 (12.9%)	9 (29%)	8 (16.3%)	13 (26.5%)	28 (57.1%)
3	Use of the EMR improves the quality of nursing/ midwifery care	12 (38.7%)	6 (19.4%)	13 (42%)	0 (0%)	6 (12.2%)	43 (87.8%)
4	Use of the EMR improves the documentation of nursing/ midwifery care	24 (77.4%)	3 (9.7%)	4 (12.9%)	19 (38.8%)	8 (16.3%)	22 (49.9%)
5	Use of the EMR improves the quality of the handover of care[a]	20 (66.7%)	7 (23.3%)	3 (10%)	11 (22.4%)	7 (14.3%)	31 (63.3%)
6	Use of the EMR improves teamwork between nurses/midwives[a]	9 (30%)	9 (30%)	12 (40%)	11 (22.4%)	22 (44.9%)	16 (32.7%)
7	Use of the EMR improves teamwork between nurses/midwives and doctors	12 (38.7%)	5 (16.1%)	14 (45.2%)	19 (38.8%)	11 (22.4%)	19 (38.8%)
8	Use of the EMR improves the efficiency of nursing/ midwifery care	8 (25.8%)	6 (19.4%)	17 (54.8%)	13 (26.5%)	17 (34.7%)	19 (38.8%)
9	The EMR is integrated with other databases and systems	10 (32.3%)	6 (19.4%)	15 (48.4%)	7 (14.3%)	6 (12.2%)	36 (73.5%)
Section B: Impact of EMR on your nursing/midwifery practice							
10	i. Use of the EMR has improved the way I practice midwifery				5 (10.2%)	5 (10.2%)	39 (79.6%)
	ii. Use of the EMR has improved the delivery of my nursing care	14 (45.2%)	7 (22.6%)	10 (32.3%)			
11	i. Use of the EMR has changed the relationship between me and the woman/women in my care				36 (73.5%)	5 (10.2%)	8 (16.3%)
	ii. Use of the EMR has improved my ability to provide woman centred care				0 (0%)	12 (30.8%)	27 (69.2%)
	iii. Use of the EMR has improved my autonomy as a midwife				0 (0%)	13 (26.5%)	36 (73.5%)
	iv. Use of the EMR has improved my interactions with the patients	6 (19.4%)	4 (12.9%)	21 (67.7%)			
12	I do not miss the triggers for care provided by a clinical pathway[a,b]	12 (40%)	7 (23.3%)	11 (36.7%)	7 (14.9%)	22 (46.8%)	18 (38.3%)
Section C: Your perceptions of patients'/women's response to the EMR							
13	i. Use of the EMR improves women's experience of pregnancy care				0 (0%)	16 (32.7%)	33 (67.3%)
	ii. Use of the EMR improves the patients' experience	6 (19.4%)	11 (35.5%)	14 (45.2%)			
	iii. Use of the EMR assists patients/women to participate in their care[c]	5 (16.1%)	10 (32.3%)	16 (51.6%)	0 (0%)	8 (16.7%)	40 (83.3%)
Section D: Training and ongoing support							
The initial training provided to use the EMR met my needs[d]		15 (48.4%)	7 (22.6%)	9 (29%)	21 (50%)	10 (23.8%)	11 (26.2%)
The on-going support to using the EMR meets my needs[e]		17 (54.8%)	7 (22.6%)	7 (22.6%)	16 (37.2%)	11 (25.6%)	16 (37.2%)

a – Questions 5, 6, 12 only had 30 responses from nurses
b – 47 responses from midwives
c – 48 responses from midwives
d – 42 responses from midwives
e – 43 responses from midwives

TABLE 2. THEMES, SUB-THEMES AND REPRESENTATIVE QUOTES FROM FREE-TEXT RESPONSES

Theme	Sub-Theme	Quotes
1. Computers affect my productivity	1.1 Potential for improved communication not always realised	I also believe it reduces and inhibits communication between multidisciplinary teams and they do not need to talk face to face about a patient. [They] just expect the nurses to read their notes – which with our workloads may not happen in a timely manner and leaves room for missed interventions (N27, 5 years' experience). If all staff utilised [the EMR] to its full capacity than yes it would improve safety and communication. The system currently is not utilised fully by all medical and midwifery staff therefore finding information at times is challenging and time consuming (M02, >30 years' experience).
	1.2 System limitations and lack of integration	[The] EMR is not a maternity friendly system. The program has too many errors in its current state to be useful or helpful. The need for triple documenting between other systems and paper creates an increased 'time with computer' instead of increasing 'time with woman'. The downtime system is also not user friendly and during an unexpected downtime we found that half of the women admitted to our ward were not on the system (M05, 5 years' experience). [The] time taken to find information is unacceptable… postnatally, [I] have to use both fixed and mobile workstations because mobile [workstations] do not have all the programs… [there's] not enough integrative hardware to run a digital hospital (M27, 20 years' experience).
	1.3 Hardware limitations	I spend a lot of time waiting for the computer to allow me to log on, can be anywhere up to 10-15 mins [minutes]…I spend time looking for recharged batteries [and] often have to borrow from other wards (N03 >40 years' experience). I wish that using the computer was a streamlined process instead of spending 20 minutes waiting for a computer to load or constantly changing batteries (N26, 7 years' experience).
2. Computers affect my relationship with the patient/ woman	2.1 Computers are a physical barrier	[I] think it [EMR] detracts from the patients experience i.e., connecting with the nurse. Patients have stated nurses are behind computers all the time (N15, 25 years' experience). It has removed my ability to truly connect with the women I care for, there is too much focus on 'keeping up to date' on the computer. I have had women comment on how much time midwives spend on the computer. How sad that they are noticing that instead of focusing on their labour/birth (M16, 7 years' experience).
	2.2 The system is impersonal and de-humanising.	How do patients feel seen and cared for when we scan them like they're being bought at a grocery store and we stare at computers clicking away instead of looking at them face to face (N27, 5 years' experience)? [The EMR] has made my care no longer personal. I feel that I am not providing woman-centred care and no longer have autonomy as a midwife because I do what a computer tells me to do (M34, 4 years' experience).
3. The EMR increases my frustration and stress	3.1 Documentation burden	The sheer volume of documentation that nurses are expected to collate is getting overwhelming. The balance between [the EMR] and actual nursing care is impacting negatively on [the] quality of nursing. [The] double documenting between your notes is also frustrating (N26, 7 years' experience). Documentation feels like it's never done. I'm repeating myself, then it's a constant cycle of picking on each other [with other midwives saying] 'this wasn't done, that wasn't done' etc. (M44, 5 years' experience).
	3.2 Concerns about patient/ woman safety	Faulty computers put all patient care, especially medication administration, at risk (N07, 3 years' experience). When computers on wheels stop or freeze in the middle of the drug rounds, [there is a] delay in medication and nursing care documentation (N19, >30 years' experience).
	3.3 Concerns about nurse/ midwife safety	I get a sore back and neck from using COWs [computers on wheels] all day, we are not provided with workstations in CCU (N01, 8 years' experience). Having to drag computers around especially with wheels that catch is harmful to nurses in causing back injuries and tripping hazards/hallway clutter (N27, 5 years' experience).

Midwives addressed the issue of lack of integration across the platform for maternity services and ideally would have preferred to have all the woman's information in one place that can easily be shared with the woman and her general practitioner (GP). Instead, midwives are using the EMR and multiple other programs to search for patient information and to document patient care. One midwife (M05) commented that the discharge summary provided by the EMR contained insufficient information for the GP, so in the best interest of the woman, midwives took the time to handwrite their notes on the printed discharge letter as well as writing in the woman's handheld record. Midwives (M04, M05, M13, M14, M18, M24, M30, M32, M39, M41 M46) provided many examples of 'double or triple documenting'.

Nurses also shared their concerns about searching for patient information, particularly in caring for the patients with extensive health history who were arriving to the ward from the Intensive Care Unit (ICU). For example, the nurses could not access patient data from ICU as ICU nurses document into the specific EMR program called Metavision (iMDsoft) and therefore the nurses relied on an ICU colleague to upload the patient's ICU data into ieMR so it can be seen when the patient arrives on the cardiac ward from ICU.

Even with the amount of data entry nurses and midwives are asked to perform each shift, there is still a lot of documentation that is paper-based or not included within the ieMR platform at all. The nurses listed documentation that is still recorded on paper to include: continuous positive airway pressure observations, food charts, consent forms, opioid withdrawal pathways, tracheostomy pathways, pacemaker/internal defibrillator/cardioversion pathways, angiogram pathways, ICU transfers and MET (Medical Emergency Team) calls. The midwives listed documentation still recorded on paper to include antenatal and postnatal forms, neonatal feed charts, birth logbooks, MET calls including neonatal resuscitation and obstetric emergencies, breastfeeding and postnatal information for the woman, postnatal depression score form, NAS (Neonatal Abstinence Syndrome) score, CTG analysis, internal referrals and any care provided during the EMR downtime.

Both respondent groups expressed frustrations about the computer workstations, particularly the mobile workstations where over a third of nurse respondents specifically mentioned battery-related problems creating barriers to timely nursing care with batteries providing only two hours of power before needing to be replaced. Nurses also mentioned lengthy 'log-ins' at the beginning of the shift and after replacing batteries, requiring the nurses to change their actions and compensate for the computers' limitations. For example, one nurse with seven years' experience wrote, "The computers [are] extremely slow, personally I am required to come into work 15 minutes early so I have a functioning computer by the time handover is finished" (N26).

Theme 2: EMR affects my relationship with the patient/woman

Nurses commented that the amount of time spent on computers was causing 'computer-centred care' rather than patient-centred care. The nurses expressed their dislike of the positive patient identification scanner linked to the EMR and compared scanning the patients' identification armbands to scanning commodities at the grocery store. Two nurses used this comparison specifically and shared how impersonal it feels as a care provider. Both nurses and midwives commented that the mobile workstations were physical barriers placed between them and the patient/woman, directly affecting their ability to establish rapport and connect with the woman/patient. Both nurses and midwives commented on the lack of space for the workstation in the patient's/woman's room feeling forced into the corridor to document thus creating an even larger barrier. Midwives suggested that handheld devices or tablets could be a solution to this problem.

Theme 3: EMRs increase my frustrations and stress

Both nurses and midwives felt the threat to patient/woman safety posed by, for example, the potential for medication errors, contributed to their stress. The nurses commented that reading the medication orders was confusing due to the layout of the medication module and the way some medications are prescribed. The nurses also had safety concerns relating to medication administration. For example, when the platform is not accessible due to maintenance, the medical team could be left without access to critical patient information, such as allergies during medical emergencies. Further safety concerns were raised by the nurses involving the physical size and weight of the mobile workstations linking this to a frequent cause of back pain. The nurses in Coronary Care Unit (CCU) said they would like to have the option of sitting down to relieve their backs however they do not have fixed workstations in CCU, only mobile workstations.

Nurses and midwives expressed feeling frustrated, stressed, and overwhelmed due the heavy 'data-entry' workload expected from them as well as finding time for the provision of direct patient/woman care. For example, one nurse with 10 years' experience wrote "For some nurses, using a computer system is very stressful on top of already unwell patients. This stress can also affect other staff members trying to help them" (N25). Midwives also stated that completing all the documentation tasks during the shift had become a source of stress due to fellow midwives complaining to each other if the documentation was not completed in time or in full. Both nurses and midwives commented that the 'documentation burden' was causing them to question their practice and consider a change in workplace/profession. A quarter of the midwives suggested the EMR platform does not suit the maternity service at all and six midwives went a little further by stating "Get rid of it [ieMR]" (M8, M16, M22, M37, M38, M48).

DISCUSSION

Nurses working in a specialist area and midwives have shared their opinions on the EMR platform in this regional Australian public health service and the associated effects on their productivity, patient relationships, and wellness. It is also worth noting, albeit somewhat ironically, that the workforce appreciated having the option of completing the questionnaire in paper. There was synergy between the responses to the Likert-scale statements and free-text responses. For example, nurses' comments that EMRs negatively affected teamwork were consistent with their Likert-scale responses. Similarly, midwives' comments expanded upon the responses of most of the midwives who disagreed that the EMR is integrated with other systems. Although more than half ($n = 18$, 58.1%) of the nurses agreed that the EMR reduces the likelihood of drug errors, the questionnaire provided the opportunity for them to express their concerns. The nurses' concerns were consistent with the midwives' Likert-scale responses, in that less than one-fifth of the midwives agreed that EMRs reduce the likelihood of drug errors. As found in other studies, nurses and midwives were concerned about the safety of the medication module of the Health Service's EMR and the potential for errors occurring due to: the misinterpretation of orders; missed orders; or incorrectly charted orders.[18-20] Obtaining user feedback on these safety concerns should be prioritised to address concerns surrounding medication orders and mitigate the risk of medication errors.

The nurses' and midwives' responses in this study align with the positive and negative effects of EMRs found in other studies.[2,3,13,18,19,21-23] As nurses and midwives are accustomed to working around time-specific duties, and often under pressure to complete tasks, it is no surprise that their comments reflected concerns around the theme of productivity. Several positive effects of the EMR on the theme of productivity were identified and align with the results from previous studies, including the ease of reading and sorting digital notes, the ability for patient data to be read by multiple clinicians simultaneously, and the ability to access an extensive health history of a woman/patient in real-time.[13,14,18,24] However, negative effects were also reported by both nurses and midwives across all three themes. Like other studies, the nurses and midwives in this study found the EMR difficult to navigate,[18] understand,[19] and customise.[21] These factors reportedly affected the nurses' and midwives' time available for patient care as some felt overwhelmed if they did not finish all tasks assigned to them by the computer program and felt that the computer system was compromising their professional autonomy.

Midwives particularly addressed the lack of integration across the system and the impact this has had on their quality of care. As in another Australian study, the midwives' primary concern was that the time constraints due to documentation across multiple platforms, such as ieMR and Perinatal Data Collection (PDC, Queensland Health), placed a strain on the opportunity to develop a relationship with women and provide clinical care.[18] Due to these time constraints, the midwives reported feeling torn between completing their digital tasks and being with woman. Midwives are no strangers to the pressure of time, however the lack of shared data between general practitioners (GPs) and hospital clinicians was identified by midwives in this study as a concern and confirms an already recognised gap in the Australian digitised health system.[25] Further understanding of the data commonly shared between maternity services and GPs could assist in improving the integration of health records, which would be beneficial to the hospital, GP, midwife, and woman.

Whilst nurses and midwives are agreeable to real-time shared patient data, the constant disruptions to care provision by system downtimes, computer battery issues, documentation burnout and lack of integration with other systems is increasing stress and exhaustion. By improving functionality of the technology and the interoperability between disparate systems, health services have the potential to relieve some of the documentation burden and burnout reported by the nurses and midwives in this study. This study supports the recommendations of Wynter et al. that the inclusion of clinical staff in the design of the EMR platform is needed to ensure beneficial outcomes to workflow.[18] The nurses and midwives in this study shared their disappointment in not being invited to give feedback on the development of the EMR platform and are of the opinion that it does not reflect the needs of each sector. Previous international and Australian studies have shown that improving the attitudes of nurses and midwives towards EMR platforms and increasing their acceptance of digitised health systems is dependent on the inclusion of clinicians in the continual development of the EMR.[13,18,21,26-28] The continued development of clinicians' computer skills and the instruction of computer skill courses at the undergraduate level would also be beneficial.[29,30]

Occupational health and safety concerns associated with computers have also been mentioned in the literature, outlining the issues of size, weight and mobility in regards to the mobile workstations.[22,31,32] Lack of space in the patient rooms was the most frequently stated occupational safety concern from this study. The nurses and midwives both shared concerns for back pain attributed to navigating small spaces with mobile workstations and standing for long periods of time due to insufficient fixed workstation access. With the ageing of the nursing and midwifery workforce, human factors approach to the design of technology needs to be considered. Future observational studies of nurses and midwives in their respective environments would be beneficial to assess physical safety issues and recommend solutions.

IMPLICATIONS

PRACTICE

The findings of this study contribute to evidence-based practice by identifying advantages and disadvantages of the current ieMR platform, identifying potential areas for improvement within the EMR.

POLICY

The results from this study can contribute to the development of policies surrounding clinical documentation and shared data and can inform the successful introduction of new technology in the future. Policies that support the inclusion of nurse/midwife feedback in future clinical application development need to be enacted.

EDUCATION

The results support the need for ongoing education for all clinicians in navigating an EMR; performing efficient documentation; recognising and reporting errors; improving team communication; and providing woman/patient-centred care. There is a need for ongoing training related to EMRs, tailored to the needs of the user groups. In fact, this has happened in the last 12 months at the hospital, with support being provided to individual wards and clinicians by the EMR implementation team.

RESEARCH

Future ethnographic research could identify how nurses and midwives adapt to overcome the perceived problems of digital documentation burden and how they can balance their professional care responsibilities towards patients/women with organisational demands.

LIMITATIONS

This study has limitations that are inherent in a cross-sectional survey. The questionnaire was developed specifically for this study, unlike a later study that had access to a validated questionnaire.[33] Additionally, the midwives' questionnaire was distributed prior to the hospital imposing restrictions on undertaking research in the clinical area associated with the COVID-19 pandemic. Foreboding about the implications of the pandemic may have led to midwives concentrating on clinical care rather than completing a questionnaire. Whilst the nurses' questionnaire was distributed some 18 months later, there were still pressures on the workforce associated with COVID-19. However, the response rate from both respondent groups was a little higher than was usual for previous staff questionnaires at this hospital. The similar response rate across the nursing and midwifery services gives strength to the conclusion of this paper, demonstrating that both nurses and midwives have valuable feedback to share regarding the design and implementation of technology in the health service. Since this study was undertaken at the one hospital, we make no claims as to the generalisability of the results to other settings. However, the findings may have relevance to other settings, particularly where EMRs are still to be introduced.

CONCLUSION

This study has provided feedback from one health service's nurses and midwives on the ieMR platform which could contribute to the development of future EMR applications and digital healthcare. While nurses and midwives both agreed having shared data in one place has been ideal as a digital hospital, the reality of shaping the EMR platform to fit all sectors of the hospital concurrently has been a lengthy and challenging process. Consequently, nurses and midwives have expressed an elevated level of stress and a sense of being overwhelmed due to repetitive data entry and challenges in overcoming limitations in the technology. The stress has led some midwives to question their chosen career. Nurses shared their concerns over the shifting organisational focus to statistics and data entry rather than the experience of the patients and staff. The number of international and national studies supporting the involvement of clinicians in the design of EMR platforms and applications further demonstrates the need for health services to adopt a human-centred design approach, regularly asking for feedback from their users, observing how this system affects all humans in its path (clinicians, patients, technicians), and implementing that feedback.[29,30] Further evaluation and understanding of nurses' and midwives' experiences can help to produce a user-friendly system, reduce clinician stress and burnout, promote acceptance of technology as well as improve health care and safety outcomes.

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RESEARCH ARTICLES

Outcomes of patients admitted to the Intensive Care Unit after Postanesthesia Care Unit boarding

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ABSTRACT

Objective: This study aimed to investigate the associations of delayed admission to the intensive care unit (ICU), due to the boarding of critically ill patients in the postanesthesia care unit (PACU), with patient outcomes.

Background: Previous literature has provided conflicting findings about whether delayed admission to the ICU is associated with suboptimal patient care and worsened outcomes. In the limited studies on ICU patients boarded in the PACU, their ICU mortality, hospital and ICU length of stay, and duration of mechanical ventilation did not differ significantly when compared with those of patients directly admitted to the ICU.

Study design and methods: This was a single-centre, prospective, observational study. Patients consecutively admitted to the ICU from January 2021 to May 2023 were enrolled. Recorded data included patient demographics, clinical severity, multi-organ dysfunction and comorbidities, and the duration of PACU boarding. Adverse patient outcomes included prolonged duration of mechanical ventilation, prolonged ICU length of stay, incidence of infections and mortality during ICU stay. The associations between PACU boarding and its duration and adverse patient outcomes were evaluated with univariate comparisons and multivariate analyses.

Results: Two hundred thirty ICU patients were enrolled, with 83 (36.1%) of them being boarded in the PACU. Median duration of PACU boarding was 72.0 (48.0-144.0) hours, with 51 (61.4%) patients staying for > 48 hours. Patients with delayed admission to the ICU were more likely to be diagnosed with surgical wound infection ($p = .023$), but less likely to be diagnosed with pneumonia ($p = .008$) compared with those with direct ICU admission. However, in the multivariate level, no significant associations were detected between PACU boarding and its duration and adverse patient outcomes.

Conclusion: Delayed admission to the ICU after PACU boarding was not associated with worsened patient outcomes, which supports the competence of PACU nurses in caring for the critically ill.

Implications for practice: These findings add to the existing evidence that the PACU can be used safely in case of ICU bed shortages.

What is already known about the topic?

- The majority of the existing studies have indicated that delayed admission to the ICU of adult patients is associated with higher mortality, while prolonged ICU and hospital length of stay have also been reported.

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- Delayed admission to the ICU may not be translated into suboptimal patient care in case critical care monitoring and treatments are provided outside the ICU.
- Boarding of critically ill patients in the PACU has not been associated with adverse outcomes, except for higher ICU mortality in case boarding duration was long.

What this paper adds

- PACU boarding was not associated with prolonged duration of mechanical ventilation, prolonged ICU LOS, infections and ICU mortality of patients.
- Even long duration (> 48 hours) of PACU boarding was not associated with worsened patient outcomes compared with direct admission to the ICU.
- The PACU can be used safely as a temporary admission location for ICU overflow patients.

Keywords: Delayed admission; infection; intensive care unit; mortality; postanesthesia care unit

BACKGROUND

Delayed admission to the ICU refers to the boarding of patients designated to need critical care in non-ICU settings until an ICU bed becomes available.[1,2] ICU bed shortages have been attributed to the imbalance between increasing demand and limited provision of critical care resources.[3,4] Although its incidence and duration vary considerably among hospitals, delayed admission to the ICU has been identified as a worldwide healthcare issue.[4-6]

The stay of critically ill patients outside the ICU can be followed by less intensive monitoring and delays in the initiation of time-sensitive care, such as antibiotic and vasoactive drug administration or haemodialysis, which could contribute to increased complication rates and adverse outcomes.[7-9] However, critical care treatments, such as non-invasive ventilation, are increasingly applied in non-ICU settings due to staff training and available specialised equipment.[10-12] Thus, delayed admission to the ICU may not be necessarily translated into suboptimal patient care. In a recent meta-analysis of 34 observational studies, delayed admission to the ICU of adult patients was associated with higher mortality [mainly during hospital or ICU stay, pooled odds ratio (OR) 1.61, 95% confidence interval (CI) 1.44-1.81].[13] Yet, in more than one-third of the included studies, mortality did not differ significantly according to delayed admission to the ICU. Besides mortality, some studies have reported that ICU or hospital length of stay (LOS) of critically ill patients boarded in the Emergency Department (ED) was significantly longer,[14-16] while in others prolonged hospital LOS was not associated with delayed admission to the ICU.[12,17]

The PACU has been traditionally used as a temporary admission location for ICU overflow patients for many reasons.[18,19] First, PACU nurses have the expertise to manage patients with hemodynamic instability and artificial airways. Second, the open-floor PACU design allows simultaneous observation of many patients. Third, there is available equipment necessary for critical care provision, such as monitors, ventilators and infusion pumps. However, since PACU care aims at the prevention of complications occurring after anaesthesia and surgery, previous reports have challenged the appropriateness of boarding critically ill patients in the PACU.[20-22] Caring for ICU overflow patients has been associated with increased workload and confusion about the treatment prioritisation by PACU nurses.[20,23] At the same time, the prevalence and volume of missed nursing care for postoperative patients have been significantly higher in the presence of even one ICU overflow patient.[24]

Existing evidence on the associations between boarding critically ill patients in the PACU and their outcomes is surprisingly limited compared with numerous respective studies conducted on patients boarded in the ED. In a retrospective study that employed 989 neurosurgical patients, outcomes did not differ significantly between those boarded in the PACU and those directly admitted to the ICU, including ICU mortality (5.2% vs. 3.8%, $p = .681$), ICU LOS (1.9 vs. 1.2 days, $p = .396$), hospital LOS (7.9 vs. 7.2 days, $p = .545$), duration of mechanical ventilation (20.5 vs. 15.0 hours, $p = .345$) and ICU readmission rate (1.9% vs. 2.7%, $p = .744$).[25] Likewise, in another retrospective study that included 2,279 postoperative patients, no significant differences were reported between those waiting in the PACU and those immediately admitted to the ICU, in terms of ICU mortality (8.6% vs. 6.7%, $p = .311$) ICU LOS (1.9 vs. 1.8 days, $p = .996$) and duration of mechanical ventilation (13.0 vs. 18.0 hours, $p = .751$).[26] However, delayed admission to the ICU for > 6 hours was associated with higher ICU mortality (OR 5.32, 95% CI 1.25-22.60, $p = .024$).

OBJECTIVE

The aims of the present study were to: (a) compare the outcomes between critically ill patients directly admitted to the ICU and those with delayed admission to the ICU after boarding in the PACU and (b) investigate the association between the duration of PACU boarding and patient outcomes. Our hypothesis was that adverse patient outcomes would be significantly more common in case of both PACU boarding and longer duration of delayed admission to the ICU.

STUDY DESIGN AND METHODS

DESIGN AND SETTINGS

This was a single-centre, prospective, observational study, which adhered to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist for observational research. The study was conducted in the Phase I PACU and the ICU of Patras University Hospital, Patras, Greece, from January 2021 to May 2023. The PACU was staffed by registered nurses whose clinical experience ranged between 5-30 years, working on three 8-hour shifts. The ICU was a closed 13-bed unit, in which adult medical, surgical and trauma patients were admitted, and was staffed by registered and licensed practical nurses. Decisions about patient care management, including diagnostic testing, drug administration, ventilatory support and discharge from the ICU, were at the discretion of the attending intensivist.

PARTICIPANTS

Intensivists decided whether a patient was designated to need critical care and were responsible for the attendance of and consultation about critically ill patients boarded in non-ICU settings. Patients were directly admitted to the ICU in case of available ICU beds. In case no ICU bed was available, patient admission to the ICU was determined in general by the “first come, first served” sequence, which means that the priority for patient admission to the ICU was based on the time sequence that patients were designated to need critical care. In rare cases, priority could be overridden for patients considered to benefit significantly by their soonest possible admission to the ICU (e.g. need for specific treatments).

All patients consecutively admitted to the ICU during the study period were screened for eligibility. The exclusion criteria were:

(a) readmission to the ICU during the same hospitalisation,
(b) delayed admission to the ICU after boarding in non-ICU settings besides the PACU (ED or medical/surgical wards),
(c) death during PACU boarding,
(d) lost follow-up due to patient transfer to the ICU of another hospital,
(e) SARS-CoV-2 infection as ICU admission diagnosis (since all these patients were directly admitted to the ICU and were not boarded in the PACU).

Eligible patients were divided into two groups: (a) those directly admitted to the ICU (direct admission to the ICU group) and (b) those with delayed admission to the ICU after PACU boarding (delayed admission to the ICU group). The duration of PACU boarding was measured from the time the patient was designated to require critical care until his/her admission to the ICU. According to the duration of PACU boarding, patients were further divided into two groups, < 48 and > 48 hours.

DATA COLLECTION

The ICU information system and patient medical records were used for retrieving and recording patient data. Collected data included:

(a) Patient demographics and clinical characteristics: age, gender, admission type (surgical/trauma or medical) and diagnosis, clinical severity, multi-organ dysfunction, and comorbidities including diabetes mellitus, traumatic brain injury, ischemic heart disease, chronic respiratory disease and malignancy.
(b) Duration of PACU boarding (measured in hours).
(c) Patient outcomes: prolonged duration of mechanical ventilation, prolonged ICU LOS (both measured in days), incidence of infections and mortality during ICU stay. ICU LOS was measured from patient admission to the ICU until death or discharge from the ICU. Duration of mechanical ventilation was measured from patient admission to the ICU until death or complete restoration of spontaneous breathing. Prolonged duration of mechanical ventilation and prolonged ICU LOS were determined for values above the median. Infections included pneumonia, bacteraemia, urinary tract and surgical wound infection.

Clinical severity and multi-organ dysfunction of patients were assessed with the Acute Physiology and Chronic Health Evaluation (APACHE) II score and the Sequential Organ Failure Assessment (SOFA) score respectively on admission to the ICU, or on PACU admission for those boarded in the PACU.[27,28] Criteria for infection diagnosis were based on the definitions proposed by the Centers for Disease Control and Prevention.[29]

ETHICAL CONSIDERATIONS

Permission to conduct this study, which involved human research, was obtained by the Hospital Ethics Committee and the Hospital Science Council (approval number 9026/2-4-2021). Before enrolment in the study, each patient’s designated healthcare surrogate provided written informed consent. To assure confidentiality of patient information, collected data was not discussed with other medical or nursing staff.

DATA ANALYSIS

Statistical analysis of collected data was conducted with the Statistical Package for Social Sciences v. 28.0 (SPSS Inc., Chicago, IL), and statistical significance was set at $p < .05$. Since all continuous variables were not normally distributed according to D’Agostino-Pearson omnibus test, nonparametric tests (two-tailed) were used, and data was presented as median (interquartile range). Categorical variables were compared with chi-square or Fisher's exact test as appropriate, and data was presented as frequencies (%). Patient demographics, clinical characteristics and adverse outcomes (as binary variables) were compared between patients with direct and delayed admission to the ICU, as well as between groups according to the duration of PACU boarding.

To evaluate whether PACU boarding, and its duration were independently associated with adverse patient outcomes, multivariate logistic regression analyses were conducted (with backward Wald elimination), and ORs with 95% CIs were calculated. Adjustments included patient age, admission type, APACHE II and SOFA score, and the presence of comorbidities. Multicollinearity was identified by values of variance inflation factors > 5. Discrimination and calibration of the multivariate models were assessed by the area under the receiver operator curve and Hosmer-Lemeshow chi-square (goodness of fit) test respectively. A Kaplan-Meier survival curve was further constructed to analyse the time-to-event association between delayed admission to the ICU and death in the ICU. Patients with direct and delayed admission to the ICU were compared with the use of a log-rank test.

RESULTS

Two hundred thirty patients were enrolled in the study. Of them, 161 (70.0%) were male and 124 (53.9%) were surgical/trauma. Median age was 61.0 (46.8-72.0) years, median APACHE II score was 20.0 (15.0-24.0) and median SOFA score was 8.0 (5.0-10.3). Among surgical/trauma patients, 40 (32.3%) had neurosurgery, 35 (28.2%) had abdominal surgery, and 25 (20.2%) had traumatic brain injury. Chronic respiratory disease ($n = 54$, 50.9%) and haemorrhagic stroke ($n = 19$, 17.9%) were the most common admission diagnoses in medical patients. The median duration of mechanical ventilation was 17.5 (6.0-41.0) days, with 115 (50.0%) patients having prolonged duration of mechanical ventilation. Median ICU LOS was 21.0 (8.8-48.3) days, with 110 (47.8%) patients having prolonged ICU LOS. Pneumonia, bacteraemia, urinary tract and surgical wound infection were diagnosed in 110 (47.8%), 216 (93.9%), 11 (4.8) and 13 (5.7%) patients respectively during ICU stay. Eighty-four (36.5%) patients died during ICU stay. Eighty-three (36.1%) patients were boarded in the PACU during the study period; of them, 32 (38.6%) were boarded for < 48 hours and 51 (61.4%) for > 48 hours. Median duration of PACU boarding was 72.0 (48.0-144.0) hours.

Demographics, clinical characteristics and outcomes of patients with direct and delayed admission to the ICU are compared in Table 1. With regard to patient outcomes, those

TABLE 1: DIFFERENCES AMONG PATIENT DEMOGRAPHICS, CLINICAL CHARACTERISTICS AND ADVERSE OUTCOMES ACCORDING TO DELAYED ICU ADMISSION AFTER PACU BOARDING AND ITS DURATION

Patient characteristics/outcomes	Direct admission to the ICU ($n = 147$)	Delayed admission to the ICU		
		All patients ($n = 83$)	< 48 hours ($n = 32$)	> 48 hours ($n = 51$)
Age [median (IQR), years]	61.0 (48.0-73.0)	60.0 (41.0-70.0)	50.5 (34.3-68.0)****	63.0 (47.0-73.0)
Gender [male, (%)]	104 (70.7%)	57 (68.7%)	21 (65.6%)	36 (70.6%)
Admission type† [surgical/trauma (%)]	52 (35.4%)	72 (86.7%)****	27 (84.4%)****	45 (88.2%)****
APACHE II score [median (IQR)]	20.0 (14.0-24.0)	20.0 (16.0-24.0)	21.0 (15.3-23.8)	20.0 (16.0-25.0)
SOFA score [median (IQR)]	8.0 (5.0-10.0)	8.0 (7.0-11.0)	8.5 (7.0-11.0)	8.0 (7.0-11.0)
Diabetes mellitus (%)	46 (31.3%)	17 (20.5%)	8 (25.0%)	9 (17.6%)
Traumatic brain injury (%)	44 (29.9%)	42 (50.6%)****	16 (50.0%)****	26 (51.0%)****
Ischemic heart disease (%)	7 (4.8%)	4 (4.8%)	1 (3.1%)	3 (5.9%)
Chronic respiratory disease (%)	88 (59.9%)	28 (33.7%)****	9 (28.1%)****	19 (37.3%)****
Malignancy (%)	17 (11.6%)	8 (9.6%)	2 (6.3%)	6 (11.8%)
Prolonged duration of mechanical ventilation* (%)	68 (46.3%)	47 (56.6%)	19 (59.4%)	28 (54.9%)
Prolonged ICU LOS** (%)	65 (44.2%)	45 (54.2%)	20 (62.5%)	25 (49.0)
Pneumonia*** (%)	80 (54.4%)	30 (36.1%)****	11 (34.4%)****	19 (37.3%)****
Bacteraemia*** (%)	139 (94.6%)	77 (92.8%)	29 (90.1%)	48 (94.1%)
Urinary tract infection*** (%)	7 (4.8%)	4 (4.8%)	1 (3.1%)	3 (5.9%)
Surgical wound infection*** (%)	5 (3.4%)	9 (10.8%)****	5 (15.6%)****	4 (7.8%)****
Mortality*** (%)	52 (35.4%)	32 (38.6%)	10 (31.3%)	22 (43.1%)

Note. ICU, Intensive Care Unit; IQR, interquartile range; APACHE, Acute Physiology and Chronic Health Evaluation; SOFA, Sequential Organ Failure Assessment; LOS, length of stay.

Note. † surgical/trauma or medical, * > 17.5 days, ** > 21.0 days, *** during ICU stay, **** $p < .05$; for all comparisons, direct admission to the ICU was used as the reference group.

TABLE 2: ADJUSTED RISK FOR ADVERSE PATIENT OUTCOMES ACCORDING TO DELAYED ADMISSION TO THE ICU AFTER PACU BOARDING AND ITS DURATION

Adverse patient outcomes	**Adjusted ORs (95% CIs) for delayed admission to the ICU**		
	All patients (*n* = 83)	**< 48 hours (*n* = 32)**	**> 48 hours (*n* = 51)**
Prolonged duration of mechanical ventilation[†]	1.04 (0.54-2.01)	1.31 (0.51-3.34)	1.16 (0.55-2.45)
Prolonged ICU LOS*	1.21 (0.63-2.32)	1.72 (0.72-4.13)	0.97 (0.46-2.05)
Pneumonia**	0.76 (0.39-1.47)	0.72 (0.29-1.74)	0.79 (0.37-1.69)
Bacteraemia**	0.68 (0.18-2.48)	0.51 (0.11-2.44)	0.84 (0.18-3.92)
Urinary tract infection**	1.02 (0.24-4.38)	0.93 (0.74-1.17)	1.24 (0.26-5.85)
Surgical wound infection**	1.75 (0.50-6.08)	2.97 (0.69-10.78)	1.17 (0.27-5.06)
Mortality**	1.39 (0.62-3.11)	0.99 (0.35-2.86)	1.73 (0.70-4.29)

Note. ICU, Intensive Care Unit; LOS, length of stay; OR, odds ratio; CI, confidence interval.

Note. For all comparisons, direct admission to the ICU was used as the reference group. For all analyses: (a) adjustment included patient age, admission type, APACHE II and SOFA score, and the presence of diabetes mellitus, traumatic brain injury, ischemic heart disease, chronic respiratory disease and malignancy; (b) area under receiver operator curve was > 0.612 with p < .001; (c) p > .705 for Hosmer-Lemeshow chi-square test, with correct classification > 62.3%.

Note. † > 17.5 days, * > 21.0 days, ** during ICU stay.

with delayed admission to the ICU were significantly more likely to be diagnosed with surgical wound infection, but less likely to be diagnosed with pneumonia. Likewise, patients of both groups with duration of PACU boarding of < 48 hours and of > 48 hours were significantly more likely to be diagnosed with surgical wound infection, but less likely to be diagnosed with pneumonia.

The findings of multivariate logistic regression analyses are presented in Table 2. After adjustment for patient demographics and clinical characteristics (which could act as confounding factors), neither delayed admission to the ICU nor the duration of PACU boarding were independently associated with adverse patient outcomes. Multicollinearity was not identified. All multivariate models demonstrated satisfactory calibration and discrimination (footnote of Table 2).

According to the Kaplan-Meier survival curve, ICU survival did not differ significantly between patients with direct and delayed admission to the ICU after PACU boarding (log rank $p = .525$, Figure 1).

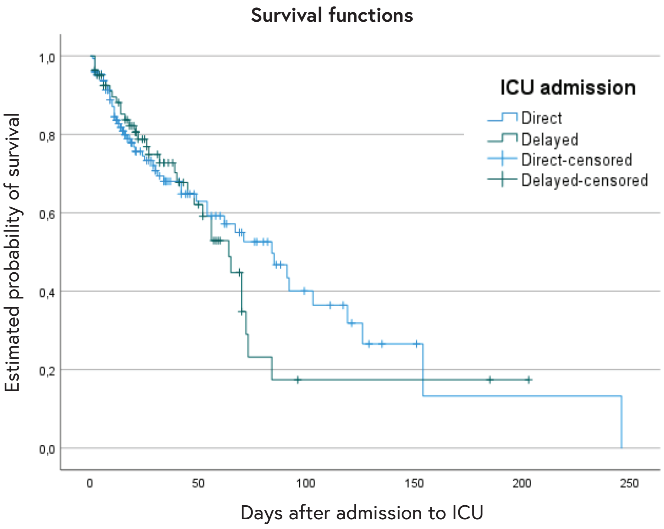

FIGURE 1: KAPLAN-MEIER SURVIVAL CURVES FOR PATIENTS WITH DIRECT AND DELAYED ADMISSION TO THE ICU AFTER PACU BOARDING

DISCUSSION

The findings of our study are in agreement with those of previous studies and add to the existing evidence that delayed admission to the ICU after PACU boarding is not followed by worsened patient outcomes compared with direct admission to the ICU.[25,26] Excluding random variation, patient outcomes depend generally on patient characteristics and the quality of care provided. To control for possible effects of selection bias and differences in patient characteristics, studied outcomes were adjusted for patient age, admission type, APACHE II and SOFA score, and the presence of comorbidities. Therefore, our findings seem to support that PACU personnel can provide safe care for ICU overflow patients until an ICU bed becomes available.

The outcomes of critically ill patients boarded in the PACU can be affected negatively by the provision of suboptimal nursing care and insufficient medical coverage by intensivists.[22] PACU nurses have reported the sense of giving less than the best care to the critically ill, while care omissions are possible due to the priority given to postoperative patients.[23] It seems therefore plausible that the longer the duration of suboptimal or missed nursing care and insufficient medical coverage for critically ill patients due to delayed admission to the ICU the higher the risk for worsened outcomes. This hypothesis seems to be supported by the previous finding that although PACU boarding in total was not associated with higher ICU mortality, this association became significant when patients who waited for ≥ 6 hours were separately studied.[26] Likewise, studies that compared the outcomes between patients directly admitted to the ICU and those boarded in the ED, have reported that ICU or hospital mortality were significantly higher for longer delays in the admission to the ICU.[6,15]

Our study was the first that enrolled patients who were boarded in the PACU for a median duration of 72 hours. In contrast, the duration of PACU boarding was particularly short in previous studies, as indicated by its median of 4.3 hours and being < 6 hours for the majority of patients.[25,26] It could therefore be speculated that the short duration of PACU boarding precluded the detection of negative effects of suboptimal or missed nursing care and insufficient medical coverage on patient outcomes, while its much longer duration in our study would allow the detection of such effects. Yet, such associations were detected neither for the entirety of patients boarded in the PACU nor for those who stayed for > 48 hours. These findings imply that both nursing care and medical coverage, even if they were suboptimal compared with the ICU, were not compromised below a critical safety level, e.g. there were no delays in the initiation of time-sensitive drug treatment or omissions that could lead to serious cardiorespiratory complications.

The fact that surgical/trauma patients were the majority among those boarded in the PACU (86.7%) but the minority among those directly admitted to the ICU (35.4%) raises concerns about the heterogeneity and comparability of these two groups. In a previous study, medical patients had significantly higher clinical severity, higher ICU mortality, and longer ICU LOS than surgical ones.[30] However, in this study, significant differences in the outcomes between surgical/trauma and medical patients were detected only for the incidence of pneumonia (35.5% vs. 62.3% respectively, $p < .001$) and surgical wound infection (11.5% vs. 0.9% respectively, $p < .001$). These differences possibly accounted for the fact that the incidence of pneumonia and surgical wound infection were significantly higher in patients directly admitted to the ICU and those boarded in the PACU respectively. In the multivariate level, both differences became non-significant after adjustment for admission type. Furthermore, studied outcomes were compared between surgical/trauma patients boarded in the PACU ($n = 72$) and those directly admitted to the ICU ($n = 52$). No significant differences were detected for any outcome, both for all patients and for subgroups according to the duration of PACU boarding.

It cannot be excluded that the definitions and characteristics of patient outcomes accounted for the lack of detecting significant associations between them and PACU boarding. Infection risk tends to increase shortly after exposure to suboptimal care (e.g. lack of compliance with infection control measures),[31] which means that the incidence of infections would be more likely to increase during the first days after admission to the ICU in case of suboptimal care during PACU boarding. Since infections were studied for the whole ICU stay, this temporal association could have been difficult to detect, while long ICU stay could have increased the incidence of infections irrespective of the care provided during PACU boarding. In addition, the duration of mechanical ventilation and ICU LOS were very long for most patients in our study compared with those in previous ones,[25,26] which could have masked possible effects of suboptimal care during PACU boarding (e.g. delayed weaning from mechanical ventilation in patients boarded in the PACU could have led to significantly longer duration of mechanical ventilation in them in case this duration was shorter in total).

LIMITATIONS AND STRENGTHS

The small sample size was the most serious limitation of our study; it cannot be excluded that significant associations would have been detected in case more patients were enrolled. It should be noted that no power analysis was conducted prior to study conduction, since it was considered impossible to enrol more patients than the existing studies due to the exclusion of those with COVID-19 and long ICU LOS.25,26 Second, the single-centre study design limited the generalisability of our findings. Third, different proportions of surgical/trauma patients among those boarded in the PACU and those directly admitted to the ICU might have favoured selection bias; it is, however, worth noticing that surgical/trauma and medical ICU patients did not differ significantly in terms of their studied outcomes. Fourth, the decisions of the attending intensivists on discontinuing mechanical ventilation and patient discharge from the ICU were not protocolised. Fifth, no adjustment was conducted for other possible confounding factors that might have affected patient outcomes, such as the variation of PACU nurse staffing levels and ICU occupancy rates.

Our study had a significant strength as well. ICU patients were boarded in the PACU for a remarkably longer time compared with previous studies, thus the detection of negative effects of suboptimal care on their outcomes would have been much more possible.

CONCLUSION

Delayed admission to the ICU after PACU boarding, regardless of duration, was not associated with worsened patient outcomes, including prolonged mechanical ventilation, prolonged ICU LOS, increased incidence of infections and mortality during ICU stay. These findings confirm that PACU nurses have adequate competence in caring for the critically ill and support that, in case of unavailability of ICU beds, the PACU constitutes a safe admission location for patients who need critical care.

IMPLICATIONS FOR PRACTICE AND RESEARCH

According to the “ICU without walls”, geographically isolated ICUs should be replaced by the provision of critical care wherever critical illness occurs, and nursing personnel employed outside the ICU should be competent and skilled in caring for the critically ill.[32] In this context, the absence of worsened outcomes of patients with delayed admission to the ICU indicates that PACU boarding is a safe solution and a primary alternative in cases of ICU bed shortages. However, ICU overflow patients can slow surgical schedules, increase missed care of postoperative patients and favour feelings of anxiety, confusion and incompetence of PACU nurses;[23,24] these negative effects should not be overlooked. Moreover, continuous admission of a large number of critically ill patients in the PACU confirms the lack of a sufficient number of ICU beds for appropriately covering population demands. Thus, PACU nurses need to improve their competence and maintain safe practice for ICU overflow patients through critical care education and training. At the same time, the availability of ICU beds is strongly recommended to increase, so that critically ill patients receive the best possible care and PACU nurses focus on their primary duty of caring for postoperative ones.[33]

The associations between the duration of PACU boarding and adverse patient outcomes are recommended to be further investigated by the use of multi-centre design and the enrolment of large patient samples, in order to detect small effect sizes and increase the generalisability of findings. Future studies should also focus on temporal associations between PACU boarding and infections, possibly by exploring their incidence during PACU boarding or the first few days after patient transfer to the ICU.

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RESEARCH ARTICLES

Effects of commencing sapropterin therapy on quality of life for children with phenylketonuria and their families: A qualitative parent interview study

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ABSTRACT

Background: Prior to 2018, sapropterin hydrochloride (BH4, Kuvan®) had not been used in Queensland, Australia, to treat sapropterin-responsive phenylketonuria (PKU). This gave our centre at the Queensland Children's Hospital the opportunity to assess the difference a new treatment makes to the quality of life of the child and family.

Study design and methods: A qualitative study design was used. Forty parents of children with a sapropterin-responsive form of PKU (one parent per family) were invited to take part in a semi-structured one-on-one interview exploring their experiences and perspectives on commencing sapropterin therapy with their child. Thirty-eight parents met the eligibility criteria, 23 consented to participate, and 21 were able to be contacted for an interview. Data collected included family background and their experiences pre and post commencement of sapropterin therapy and its impact on their child(ren), diet, and physical and psychosocial wellbeing.

Results: Four key themes emerged from thematic analysis: a) psychosocial wellbeing, b) child health and nutrition, c) family economic benefits, and d) parent-child interactions. Overall, parents reported positive experiences and reduced impact of PKU on child, parent, and family quality of life

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following initiation of sapropterin therapy. The majority reported a sense of relief and optimism and expressed that they were able to manage their child's PKU more effectively than before.

Conclusions: Sapropterin therapy is associated with physical and psychosocial benefits for children and families, including improved psychosocial wellbeing, parent-child relationship quality, and child health and nutrition.

Implications for research, policy, and practice: Commencement of sapropterin therapy can result in physical and psychosocial benefits for children with phenylketonuria and their families. Longer-term follow-up studies are warranted.

What is already known about the topic?
- PKU presents numerous and diverse challenges for children and their families and can negatively impact quality of life.
- Adhering to strict dietary management requirements can be particularly challenging for children and adolescents.
- Sapropterin therapy, a relatively new treatment for PKU in Australia, can enable less severe dietary restriction and greater liberalisation of the low phenylalanine diet.

What this paper adds
- Parents report considerable overall benefits for their child and family after commencing sapropterin therapy.
- Parents perceived improved child and family psychosocial wellbeing, parent-child relationship quality, and child health and nutrition, as well as socio-economic benefits.
- Since many parents experience uncertainty and anxiety in relation to commencing sapropterin with their child, families may benefit from psychosocial support and monitoring before, during, and after the commencement of therapy.

Keywords: Child Health; Childhood Illness; Family; Metabolic; Quality of Life; Phenylketonuria.

OBJECTIVE

Prior to 2018, sapropterin had not been used in Queensland, Australia, to treat sapropterin-responsive phenylketonuria (PKU). This qualitative study aimed to explore the experiences of families of children with PKU when commencing sapropterin therapy.

BACKGROUND

Phenylketonuria (PKU) is a rare Inborn Error of Metabolism (IEM) with an incidence of approximately 1 in 10,000, resulting from a deficiency of the enzyme phenylalanine hydroxylase and characterised by elevated blood phenylalanine (Phe) levels.[1] Newborn screening for PKU leads to rapid identification and immediate commencement of dietary intervention (i.e., adherence to a low-Phe diet) to prevent severe neurological manifestations.

Dietary intervention varies from patient to patient but may involve considerable restrictions in natural protein intake from food and breastmilk or infant formula, requiring supplementation with specialised Phe-free formulas and speciality low protein foods to support adequate nutrition and growth. Most children require different (low protein) meals from the rest of the family and natural protein intake is closely monitored to ensure it stays within daily limits. The rigours of dietary management can therefore be arduous for children and families, especially at key times in children's normal psychosocial and cognitive development (e.g., toddlerhood, adolescence) which can, in turn, affect compliance.[2] Thus, metabolic control and compliance can be suboptimal during key stages of normal childhood development. Furthermore, a systematic review has suggested that outcomes with dietary treatment alone are suboptimal in terms of neurocognitive, psychosocial, quality of life, growth, nutrition, and bone pathology measures.[3] In addition to the complexity of managing dietary interventions, studies have demonstrated the impact of PKU on various aspects of quality of life and psychosocial adjustment for children and their families.[4-9]

Sapropterin dihydrochloride (Kuvan®), a synthetic form of tetrahydrobiopterin (BH_4), was approved in Australia in December 2007 as the first drug treatment for PKU.[10] It is administered orally to lower blood Phe levels and increase Phe tolerance for those individuals who have a proven sapropterin responsive form of PKU. It has been used worldwide for many years and treatment protocols have been developed, enabling varying degrees of liberalisation of the low-Phe diet.[11,12] Responsiveness is assessed by commencing sapropterin dosing (20 mg/kg/day) and checking Phe levels at 24 hours and then weekly for 4 weeks, with a decline in Phe levels of around 30% indicating responsiveness.[13]

Approximately 25-50% of patients are found to be sapropterin-responsive and can then commence long-term sapropterin therapy of 5-20 mg/kg/day in conjunction with a relatively liberalised (although still Phe-restricted) diet.[13] Long-term therapy continues as long as patients remain under the care of a metabolic multidisciplinary team who provide regular reviews and refine diet plans to ensure Phe levels remain within the target range.

Given the significant impact of strict dietary controls on children's and families' lives, relaxation of diet has the potential to impact psychosocial wellbeing. However, studies of changes in quality of life for patients treated with sapropterin have shown mixed findings. Two studies indicated improvements in quality of life and three studies found no effects of sapropterin therapy on self-reported quality of life.[12,14,15-17] Finally, Huijbregts and colleagues found improvements in quality of life for adults with PKU but not children with PKU.[18] Feldman and colleagues suggested that the self-reported measures they used may not have been sensitive enough to detect changes and called for more research to examine the nature of changes associated with sapropterin therapy.[17] Similarly, Demirdas and colleagues noted that qualitative reports suggested that patients were experiencing substantial differences in their day-to-day life which were not being captured by the quality of life questionnaire.[15]

In summary, although sapropterin therapy often allows substantive relaxation in dietary control while maintaining Phe levels within recommended guidelines, little is known about the lived experience of children and their parents following the commencement of treatment. This is a significant gap in our understanding of how effective the treatment is for children and their families, and therefore in our ability to effectively communicate treatment expectations. Insight into the lived experience of children and families following treatment commencement may help inform educational strategies to support realistic expectations.

In 2019, sapropterin gained funding by the Pharmaceutical Benefits Scheme (PBS) in Australia to provide a treatment option for children under the age of 18 years who have a sapropterin-responsive form of PKU (≥30% reduction in Phe following a sapropterin test load), thereby providing an opportunity to explore parents' experiences when their children commenced treatment. This study used a qualitative approach aiming to provide a better understanding of the impact of commencing sapropterin therapy for children and their families via parent interviews.

METHOD

A qualitative case study design was used.

PARTICIPANTS

Forty parents of children with PKU attending the Queensland Lifespan Metabolic Medicine Service (QLMMS) at the Queensland Children's Hospital (QCH) were screened for eligibility against the following inclusion criteria: (i) parent (aged 18 years or older) of a child diagnosed with a sapropterin-responsive form of PKU, (ii) child had commenced sapropterin therapy. There were no exclusion criteria. Thirty-eight parents met eligibility criteria and were mailed a written invitation to participate, followed up by telephone call(s) to assess interest. Of 38 parents, 23 (60.5%) consented to participate in the study. Of these, two were not able to be contacted to arrange an interview, leaving a final sample of 21 parents.

Participant characteristics are reported in Table 1. Most were mothers, university educated, employed, and able to meet essential expenses. Most children were living in their original family, with two parents and one sibling, and there were more girls than boys. In the four families with multiple children (two) with PKU, both children were receiving sapropterin therapy.

All children were prescribed 20 mg/kg/day of sapropterin. Children's mean blood Phe levels in the 6-months pre- and post-commencement of sapropterin were 331.08 µmol/L (SD = 78.71) and 290.44 µmol/L (SD = 101.71), respectively. Average pre-sapropterin natural protein allowance was 11.0 g/day (SD = 7.2). A subset of 15 children (pre-sapropterin protein allowance M = 8.1 g/day) continued counting protein intake once on sapropterin therapy, with a mean increase of 6.5 g/day. The remaining 10 children (pre-sapropterin protein allowance M = 15.3 g/day) no longer counted protein intake once on sapropterin therapy and had advanced to consuming allowed core food groups as per the Australian consensus method of dietary liberalisation. All children continued to receive amino acid supplementation via Phe-free formula while on sapropterin.

PROCEDURE

Approval to conduct the research was granted by the Human Research Ethics Committees of Children's Health Queensland (HREC/20/QCHQ/67483) and the University of Queensland (2020002347). Eligible parents were mailed an invitation letter and printed information and consent forms. A member of the research team (EE) contacted each family by phone within two weeks of the mailout to discuss the study with parents, answer any questions, and obtain written consent from those who wished to take part. Parents were recruited into the study from December 2020 to April 2021, and interviews were conducted from January 2021 to April 2021.

One parent per family (the primary caregiver) was invited to take part in a semi-structured one-on-one interview exploring their experiences and perspectives on commencing sapropterin therapy with their child. Families were interviewed around sixteen months after their child commenced treatment with sapropterin (M = 16.30 months, SD = 4.67, range 7.03- 22.80 months). The interview opened with questions about family background before exploring the impact of commencement of sapropterin therapy

TABLE 1: CHARACTERISTICS OF PARENTS (*N* = 21) AND CHILDREN (*N* = 25)

Variables	*M*	*SD*
Parent age (years)[a]	41.38	9.15
Child age (years)[b]	9.13	5.59
Number of children in household (total)[c]	2.00	0.78

Variables	%	*n*
Number of children in household with PKU[d]		
1	81.0	17
2	19.0	4
PKU diagnostic category[e]		
Classical PKU (>1200umol/L)	20.0	5
Mild PKU (600-1200umol/L)	64.0	16
Hyper-Phe (120-600umol/L)	16.0	4
Child conditions		
Emotional or behavioural problems	12.0	3
Physical disability	4.0	1
Other chronic health condition	24.0	6
Child sex		
Male	28.0	7
Female	72.0	18
Parent relationship to child		
Mother	90.5	19
Father	9.5	2
Relationship status		
Married/de facto	95.2	20
Widow/er	4.8	1

Variables	%	*n*
Household		
Original family	85.7	18
Step-family (2 parents, one being a step-parent)	9.5	2
Sole parent family	4.8	1
Parent education		
High school	9.5	2
Trade/college	19.0	4
University degree	42.9	9
Postgraduate degree	28.6	6
Parent employment		
Full-time	33.3	7
Part-time	61.9	13
Not working	4.8	1
Ethnicity		
Caucasian	90.5	19
Asian	4.8	1
First Nation	4.8	1
Able to meet essential expenses[f]		
Yes	95.2	20
No	4.8	1
After expenses can afford		
Not much	0	0
Some things	38.1	8
Most things	61.9	13

[a] Range 29-65 years.

[b] Range 1.42-18.67 years.

[c] Range 1-4 children.

[d] All children with PKU in household were receiving sapropterin therapy.

[e] Diagnostic category based on Phe level at time of diagnosis: classical PKU >1,200 µmol/L, mild = 600–1200 µmol/L, hyper-Phe = 120–600 µmol/L.

on children's PKU symptoms, dietary management, and physical and psychosocial wellbeing; the practical, social, and emotional impact of PKU on child and family; impact of children's dietary restrictions/liberalisation on day-to-day life; and impact of sapropterin therapy on the need for Phe-free amino acid supplementation.

To enable the inclusion of regional and remote families in the study, families could choose to be interviewed by phone, via Zoom videoconferencing, or in-person at the Queensland Children's Hospital or The University of Queensland. Interviews took a median 21 minutes (range 14-43 minutes). Parents were given the opportunity to review the written transcript and clarify their responses at the end of their interview. Interviews continued until all parents who had consented to participate had been interviewed; no stopping criteria were used because of the small number of eligible families.

MATERIALS

PKU management information (e.g., diagnosis details, PKU diagnostic category, pre- and post-sapropterin daily protein allowance, routinely-monitored blood Phe levels) was obtained from the children's treating team (QLMMS clinicians) with parents' consent. The Family Background Questionnaire was used to collect sociodemographic information including parent age, child age and sex, ethnicity, family composition, and education.[19]

DATA MANAGEMENT AND ANALYSES

All parents elected to be interviewed via Zoom videoconferencing. Interviews were recorded via Zoom videoconferencing software and transcribed verbatim. Accuracy of transcriptions was checked by EE, and interview transcripts were de-identified using unique participant codes prior to analysis. Original audio files and de-identified transcripts were stored separately on a secure drive within the University computer network.

Descriptive statistics were used to describe the sample using demographic and child health history data. Qualitative data were analysed in line with the framework for reflexive thematic analysis recommended by Braun and Clarke,[20] and followed Clarke and Braun's six-step protocol: (1) familiarisation with the data, (2) coding the transcripts, (3) generating initial themes, (4) reviewing emergent themes, (5) defining the themes, and (6) writing up the findings.21 The initial coding was done by JA and subsequently checked by AM and AEM to ensure inter-coder reliability. To ensure the credibility and dependability of the results, frequent discussion and revision of emerging concepts was undertaken as a team prior to the synthesis of codes and generation of themes across the whole dataset. Results were presented according to the standards for reporting qualitative research.[22]

RESEARCHER CHARACTERISTICS AND REFLEXIVITY

All study authors have extensive experience working with parents and children in both clinical and community settings. The study was conceived by AI (nurse practitioner), CA (registered nurse), AE (metabolic dietitian), SS and JS (clinical nurse and registered nurse respectively) who have between 5 and >20 years' of experience caring for children with PKU and their families. Each had a pre-existing professional relationship with the participating parents and were key members of the children's health care team at the QLMMS. The interview schedule was developed by AEM and AM, who are a paediatric nurse and clinical psychologist, respectively, both with clinical and research experience in working with families of children with chronic health conditions. The interviews were conducted by EE, a developmental psychologist, and data were analysed by JA, a clinical psychologist, with input from the broader research team. Neither EE nor JA had prior relationships with the families who took part in this study.

RESULTS

The thematic analysis revealed diverse but overarching experiences for parents whose children had commenced sapropterin therapy, and four core themes emerged: a) psychosocial wellbeing, b) child health and nutrition, c) family economic benefits, and d) parent-child interactions. Overall, parents reported positive experiences following initiation of sapropterin therapy, and the majority reported a sense of relief and optimism. Generally, parents expressed that they were able to manage their child's PKU more effectively than before.

THEME 1: PSYCHOSOCIAL WELLBEING

The time following PKU diagnosis and the period preceding the initiation of sapropterin therapy was quite turbulent for many parents. Managing a child whose diet and social interactions require constant monitoring contributed to apprehension and uncertainty, and most described feeling anxious about the future and having concerns around their child's treatment outcome. Family and child psychosocial experiences pre- and post-initiation of sapropterin therapy were captured in the following sub-themes:

1.1 Parental apprehension

Parents had mixed feelings around starting their child on sapropterin.

> *Well, it was a bit nerve-wracking because we didn't know if his body would respond…* (Parent M)

> *It was exciting….and nerve-wracking…there was a lot of unknowns still…* (Parent R)

> *I felt anxious…I felt that her levels were probably very high and of course I didn't know if the Kuvan® would bring that level down…when we got the news that she was responsive it was great. It was actually fantastic…it was a really happy and joyful time for our whole family.* (Parent B)

> *I'm a little bit lost…I am still struggling a little bit…it's been a very long process in understanding around PKU…* (Parent O)

While many parents were optimistic about the treatment outcome, some still expressed concerns about sapropterin administration and its effectiveness.

> *The most difficult part was…the number of tablets that she had to take each day…that's kind of the biggest issue…* (Parent U)

> *…let them have as much fruit and vegetables as they want without counting…I found that really hard to not count, because I was like, I – I'm not in control. I feel like I'm just hanging around waiting for the result to come back to let me know whether I'm doing it right or not…So, I did have a lot of anxiety about just letting go and trying a new way of eating…there were times where I'd be so worried that I would not be willing to try things…* (Parent C)

1.2 Social interactions

Parents expressed varying degrees of change in their family's social life. For many families, initiating sapropterin therapy and their child's positive response to treatment brought a sense of relief and freedom to engage more freely in social activities such as birthday parties and dining out due to less restrictive dietary requirements.

> *Socially…it has definitely had a bigger impact…she can sit for morning and afternoon tea, and she doesn't have to have, like a special kind...it's allowed her to participate – like share in a birthday celebration…* (Parent O)

> *Kuvan® has changed the variety of food that they can eat and their social activity…a very considerable improvement for their quality of life.* (Parent D)

> *We do enjoy…going out to eat more than before…because they can choose more…It's easier than before...* (Parent J)

> *…having a birthday party and they might go for lunch somewhere, and we'll drop her off and…she never feels out of the group…* (Parent V)

> *…it's much easier her going to social events, so whether that's to a friend's house or school…again, is much, much easier than it used to be…* (Parent B)

1.3 Child psychological wellbeing

Parents also reported improvements in the mental, emotional, and behavioural functioning of their children post-sapropterin initiation.

> *…less resentful of her condition…has a lot more choice in what she can have and she's very happy…I just think that attention level…that's improved.* (Parent K)

> *Before Kuvan® …by the afternoon…couldn't do any schoolwork and then she was talking and then she was distracting and she was getting into trouble...she can focus so much better…finished exam in time and she's excited about it…she never would have been able to do that before…and she's less emotional…* (Parent Q)

> *…he was very withdrawn…I think his confidence probably came after Kuvan®…* (Parent H)

> *School has been much better since the Kuvan®, so much, so much easier, don't have to worry about it…* (Parent Q)

THEME 2: CHILD HEALTH AND NUTRITION

This theme underscored the changes that parents perceived in their children's physical health and food choice/nutrition post-sapropterin initiation.

2.1 Child physical health

Most parents in the study perceived marked improvements in the physical health of their children. Comparing the pre- and post-sapropterin experience, parents expressed that they noticed significant effects of treatment on the physical wellbeing of their children including lower Phe levels, more effective sleep, and higher energy levels.

> *…she's [child's] definitely got a lot of energy now.* (Parent W)

> *…her energy levels, if anything, have improved…sleeps a bit more in the morning…overall she's more well post-Kuvan® than pre-Kuvan®.* (Parent N)

> *She [child] responded really well to Kuvan® so her levels have been really, really low since she's been on that.* (Parent X)

> *[Child] did at first complain of a sick stomach…they would have limited breakfast because they were so full. At first – where now they're a lot better, you know, they can balance, it's a little bit of liquid than a whole cup of juice to have every tablet. So that made a big difference.* (Parent A)

> *Kuvan® has definitely made things a lot easier for us in terms of food, whether or not it's just his immune system has gotten better, but he doesn't seem to get sick very much...* (Parent H)

> *…definitely, we can see a difference in…her level of tiredness…we are using Kuvan® to keep her level…lower, and I believe – or my observation is – that that helps her sleep better.* (Parent B)

2.2 Child food choice/Nutrition

Managing children's Phe levels required parents to carefully regulate the amount of protein intake at every meal from birth, a task which parents described as both complex and demanding given the need for constant monitoring of what and how much the child eats.

> *…trying to manage this very complex diet again and trying to make it work. So, yes, it can be very worrying, but you want to make sure you're doing the right thing because it does affect their brain function…* (Parent A)

Despite ongoing complexity around diet, most parents described their experience post-initiation of sapropterin as positive and rewarding for both the child and the family. A child's newfound ability to eat a wider variety of foods in unmeasured quantities was the greatest highlight for most parents.

> *It definitely makes it easier because we have more protein to play with in the day… because – increased his tolerance by 30%, [broader range of products] makes life easier for us [family] including grandparents looking after him….* (Parent I)

> *The food that they can eat at the moment is much more than before…I don't have to worry about if they've had too much steak for this meal…* (Parent D)

> *It's definitely allowed us to increase her diet a lot more and probably a lot quicker than what we would have been able to do otherwise…it's definitely a lot easier being able to just buy…rather than having to get a low protein option…* (Parent X)

> *It's easier because she has more allowance. So, her natural protein allowance is easier. That gives her access to more foods that she likes…I don't have to weigh or measure anymore…* (Parent B)

> *I no longer have to use pharmaceutical grain-based food… more flexibility around not having to weigh stuff…and cooking different meals, and without having to be on her like a hawk…to make sure she doesn't eat anything that she's not meant to eat.* (Parent O)

THEME 3: FAMILY SOCIO-ECONOMIC BENEFITS

This theme describes parents' perceptions of socio-economic benefits of having their child commence sapropterin.

3.1 Family food expenses

Most parents expressed that sapropterin reduced the financial pressure associated with having to purchase specialty low-protein foods, which tend to be costly. Parents felt that spending less on specialty low-protein foods had a direct financial benefit for their family.

> *I don't have to spend much money trialling different foods, having Kuvan® took that weight off not having to be so concerned about what she was eating.* (Parent O)

> *I think it's been beneficial, and I can see the benefits… we're not spending as much money on the specialised low protein products.* (Parent U)

3.2 Family dietary freedom

Having a child with PKU typically involves cooking a variety of meals, including special low-protein meals, to cater to the dietary needs of every family member on a daily basis. When eating out, families had previously needed to grapple with the challenge of always having to ask for special menus or modified meals to accommodate their child's restrictive diet. Many of these challenges had eased since starting sapropterin.

> *We always sit down at the dinner table, and we always eat together…where once upon a time we'd have to speak to the waitresses and chefs to tweak it to make it acceptable for her to eat, where now we don't have to do that. It's fantastic.* (Parent T)

For many parents, sapropterin brought a sense of relief and enhanced freedom to access, buy, cook, and enjoy a variety of foods with less restrictions due to protein content.

> *She is certainly enjoying food at the moment…family meals now look more similar…* (Parent K)

> *Now it's more like we just cook our meal and then just add the meat in, you know it could be more of a family meal, we can eat more of the same things.* (Parent F)

> *They've got more protein to play with…that's made life easier. They've been able to probably eat a little bit more normal food, like food that you can buy from the groceries.* (Parent C)

Theme 4: Parent-child interactions

Some parents expressed feelings of stress and frustration in their effort to control their child's Phe levels prior to commencing sapropterin, which impacted how they related to the child.

> *I do worry, and I worry because I can see that not managing your Phe levels has this really difficult negative spiral…kids with this disorder are at much, much higher risk of mental health issues…* (Parent B)

> *Them having the high levels was stressful me knowing that they were deliberately pushing the levels up.* (Parent Q)

In contrast, most parents expressed relief and spoke of their excitement about the change in the quality of their relationship with their child after initiating sapropterin therapy. Parents reported meaningful gains including spending more quality time together at home and elsewhere, better communication, improved teamwork within the home, and better socialisation.

> *We see that it's a bit of a team approach at doing things…a bit more social freedom for us as a family…* (Parent K)

> *We actually enjoy spending that time together…it's not a constant battle.* (Parent Q)

> *When it came to the realisation that the Kuvan® was successful for [Child], it was a celebration. We went out to breakfast, and we cried over bacon and eggs together, we couldn't believe that this was real.* (Parent T)

> *…yeah, have that, have that open chain of communication...* (Parent W)

DISCUSSION

PKU presents numerous and diverse challenges for children and their families, and the advent of sapropterin therapy has the potential to dramatically change families' day-to-day experiences of managing this complex condition. Nevertheless, prior studies examining the effects of sapropterin therapy have reported mixed outcomes,[12,14-18] and no studies to our knowledge have examined the lived experience of parents whose children with PKU commence sapropterin therapy. This study used a qualitative design, with a relatively large sample size, to examine the experiences and perceptions of parents following their children's commencement on sapropterin therapy. Four main themes with multiple sub-themes were described, with each theme suggesting that parents were experiencing considerable overall benefits for their child and their family after commencing sapropterin therapy.

Psychosocial wellbeing of both parent and child was a central theme that parents noted being important both before and after starting sapropterin therapy. Most parents described experiencing feelings of apprehension, uncertainty, and anxiety about the future and their child's treatment outcome prior to starting therapy. Many parents described having mixed feelings about their child commencing sapropterin, and some continued to have ongoing concerns about the administration and effectiveness of this treatment. Importantly, however, parents noted that they could see significant improvements in their child's mental, emotional, and behavioural functioning post-sapropterin initiation. One important element which may have contributed to improved wellbeing was the ability to participate in social activities and events more easily due to less need for dietary restriction, which brought a sense of normalcy for children and families. These results align with those of a recent UK study, which reported improvements in caregivers' mental health and reduced family impact 6-months after children's commencement of sapropterin.[23]

A second important theme related to the broader dietary choices that children now had, and parents' perceptions of their children's physical health and nutrition. The introduction of sapropterin did not eliminate the need to monitor and regulate children's diets, but it enabled a significant easing of the day-to-day burden of dietary intervention and allowed children the choice to eat a wider variety of foods. Parents also noted that their children had better sleep and higher energy levels, and, importantly, that their Phe levels remained low. PKU is associated with deficiencies in dopamine and serotonin, which are neurotransmitters important to sleep regulation;[24] however, very few studies have examined sleep in PKU. While reduced sleep quality and increased daytime sleepiness have been reported in studies with adults no differences have been found between children with early-treated PKU and healthy controls.[24-26] To the best of our knowledge there is no research examining the effect of commencing sapropterin on the sleep of children with PKU, and our data support this as an area for future research.

The third theme focused on the perceived socio-economic benefits, especially the reduction in financial burden associated with having to purchase costly specialty foods and supplements. Associated with this was a sense of freedom, both at home and when eating out, around the broader range of foods the whole family could now consume. In Australia, patients with PKU who are compliant with regular Phe monitoring and require a low-protein diet are eligible for a monthly payment of AUD$279 through the Inborn Errors of Metabolism program to assist with purchasing low-protein foods.[27] While this helps to offset costs, specialist low-protein foods remain expensive; for example, a packet of low-protein pasta (AUD$9.90-$13.50) is considerably more costly than a standard supermarket equivalent (AUD$0.90-$3.50). The dietary liberalisation that resulted from the commencement of sapropterin therapy was therefore associated with reduced financial pressures for families.

The final theme focused on perceived benefits to the parent-child relationship. Parents noted that the demands of rigorous dietary management associated with PKU had negatively impacted their relationship with their children. The commencement of sapropterin resulted in marked improvements in how families spent their time together, how well they got along, and the sense of belonging to a team.

The results of this study are consistent with previous research which has shown positive effects on psychosocial outcomes and quality of life following commencement of sapropterin,[12,14,23] and provide a unique view into the lived experience of parents and children shortly after the commencement of therapy. Overall, the experiences of parents who participated in this study were positive and suggest that families could reasonably expect to derive a range of child-, parent-, and family-level benefits from commencing therapy, many of which could persist for as long as therapy is effective. Thus, results may inform discussions with families who are considering commencing sapropterin therapy; however, additional follow-up of families is needed to understand longer-term experiences and effects.

Although parents reported significant positive changes following the commencement of sapropterin for their children and families, the lead-up to responsiveness testing and commencement of therapy emerged as a challenging time for parents, who described anxiety and worry about whether and how their child would respond to treatment. Even once children responded well and commenced therapy, some parents experienced a degree of ongoing stress and anxiety around liberalising their child's diet, and worried about keeping their child's Phe levels within the target range while they were experimenting with new foods and quantities. This has important implications for care planning for families who are being offered sapropterin therapy and suggests that families may benefit from psychosocial support and monitoring before, during, and after commencing sapropterin.

LIMITATIONS

PKU is a rare disease and, as such, it is challenging to get large numbers for a study like this from one centre. Despite this, we recruited more than half of the eligible families in Queensland and data saturation was achieved; however, the views of those parents who declined to participate, and whether they are different from parents who did participate, are unknown. Another limitation was that we were not able to compare responses of parents whose children had different sub-types of PKU and potentially differential treatment responses to sapropterin. In addition, while we captured the views of parents, we did not interview children, and this is an ongoing gap in the literature. Gaining insight into the experience of children affected by PKU is an important consideration for future research.

CONCLUSIONS

Sapropterin is a relatively new treatment for PKU in Australia and has the potential to have great benefits to lifestyle and dietary freedom. This study demonstrated that parents overall had a positive outcome and experience of the therapy with benefits for psychosocial wellbeing, parent-child relationship quality, child health and nutrition, and socio-economic benefits.

IMPLICATIONS FOR RESEARCH, POLICY AND PRACTICE

Commencement of sapropterin therapy can result in physical and psychosocial benefits for children with phenylketonuria and their families; however, families may benefit from psychosocial support and monitoring before, during, and after commencing sapropterin. Longer-term follow-up studies are needed to understand longer-term experiences with, and effects of, sapropterin for parents and children.

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REVIEWS AND DISCUSSION PAPERS

Implementation of nasal high flow therapy for infants with bronchiolitis: An integrative review

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ABSTRACT

Objective: Identify factors relevant to the implementation of nasal high flow for infants with bronchiolitis in rural and remote contexts.

Background: Healthcare services in rural and remote Australia must be resilient in responding to paediatric respiratory illness and provide equitable access of care to the tertiary contexts. Retrievals cannot be the only option to provide equitable care, particularly in examples of cyclones reducing aeromedical retrieval services. Nasal high flow (NHF) therapy is available for use in tertiary contexts for treating infants with respiratory illness. However, its use in rural and remote services is inconsistent and implementations to support routine implementation into this context are unknown.

Study design and methods: An integrative review was completed using an adapted implementation science framework. The COM-B (Capability, Opportunity, Motivation – Behaviour) framework was used to structure and analyse the results in alignment with translatable clinical care setting implementations. Seven databases were searched using specified search terms such as nasal high flow therapy, bronchiolitis, and implementation.

Results: The original search terms 'rural' and/or 'remote' yielded zero results and were therefore removed from the search criteria. Sixteen publications were included in the final analysis that yielded 73 implementation factors. Eight related to capability, 61 were opportunity factors and four were motivation factors. Many of the factors were relating to the local context level, such as using observation regimes. One study (two publications) explicitly reported using an implementation framework where context was considered as an important component in identifying implementation strategies.

Discussion: Implementation strategies included staff training (capability). The opportunity for staff to use NHF was the most common factor with using guidelines. The least represented motivation strategies focused on the clinician's confidence to use NHF therapy.

Conclusion: The lack of reported NHF studies in rural and remote hospitals highlights a knowledge gap. Implementation science is recommended for use in contexts such as the rural/remote setting where the context is unique and requires targeted implementation strategies.

Implications for research, policy, and practice: Research exploring the use of NHF therapy should consider the unique rural and remote context using appropriate implementation strategies.

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Implementation science has shown that factors such as local champions, guidelines, use of observational data, and having locally tailored training and supportive approaches does improve the implementation of NHF therapy. The authors recommend these strategies be applied in rural and remote contexts to inform future research, policies, procedures, and practices that will promote and support clinicians' confidence and ability to implement NHF therapy.

What is already known on the subject:
- NHF therapy is used for infants with bronchiolitis within the tertiary environment.
- NHF is used outside of paediatric intensive care units.
- Implementation science frameworks hasten evidence-based clinical practice routine uptake.

What this paper adds:
- Identifies a gap in the literature reporting implementation factors relevant for NHF therapy.
- Identifies no published literature reporting NHF use in rural and remote contexts.
- Describes, using an implementation framework, relevant factors for the use of NHF therapy in rural and remote hospitals.

Keywords: Implementation science, oxygen therapy, paediatric, remote, respiratory illness, rural.

INTRODUCTION

RATIONALE

Paediatric respiratory disease is a significant problem that incurs great emotional distress, life disruption and financial costs,[1] particularly in Australian rural and remote communities where respiratory disease disproportionately affects Aboriginal and Torres Strait Islander populations.[2,3] Aboriginal and Torres Strait Islander infants are more likely to be hospitalised, have more severe illness, and be susceptible to comparatively poorer outcomes than their non-Indigenous counterparts.[2-4] In a retrospective case review conducted in the Northern Territory, nearly one third (248 out of 789) of the paediatric aeromedical retrievals were due to bronchiolitis and pneumonia.[3] Of the children retrieved, 14 were ventilated, 10 required continuous positive airway pressure (CPAP) and one required bilevel positive airway pressure (BIPAP).[5] The review did not comment on any other oxygen delivery devices, such as nasal high flow (NHF) therapy.

NHF therapy is an oxygen delivery device that uses nasal cannulas to deliver higher concentrations of heated and humidified oxygen in the inspiratory breathing phase.[6] The efficacy of NHF therapy has been established in reducing escalations of care for use when standard oxygen delivery devices are insufficient in the tertiary and regional hospital settings.[5,7] NHF therapy is available to children in tertiary facilities, if needed.[7-9] However, children in rural and remote hospitals do not have equitable access to NHF therapy, with the current use of NHF therapy ranging from inconsistent to absent.[10] Current practice in most rural and remote hospitals includes children receiving oxygen therapy through standard low flow devices, such as simple nasal prongs. Any deterioration in the child's condition would normally result in escalation to retrieval to a tertiary facility and/or intubation/ventilation.[10] The unavailability and underutilisation of NHF therapy is largely due to there being no guideline for its use within the rural and remote context.[10] This has resulted in inequitable access to care for rural and remote children, who require NHF therapy, as they must rely on retrievals to tertiary hospitals to access this treatment option.

The escalation to retrieval of a child from a rural and remote site comes with many costs, both financial and psychosocial. A Retrieval Services Queensland representative quoted that an average cost for a child to be retrieved from Weipa to Cairns by a fixed-wing aeroplane as $8000.00; a retrieval of a child from Thursday Island to Cairns by a fixed wing aeroplane and helicopter averaged $23,000.00 (both locations are in Far North Queensland, Australia) (telephone conversation, 2 September 2019). Estimated retrieval costs are only based on the transportation component and not the cost of living away from home, loss of income, care of other family members, and the psychosocial impact of having to leave your home for possibly long periods of time.

NHF therapy is not a panacea for managing all children with respiratory illness and the benefits of its use are still being determined through ongoing research.[7,8,11] However, current evidence does demonstrate the effectiveness of NHF therapy, in children with respiratory illnesses, when low flow oxygen devices are insufficient.[7-9,12] Therefore, it is vital to better understand the reasons that impede the implementation of NHF therapy in the rural and remote context. Implementation Science (IS) can help clinicians understand barriers and enablers to the implementation of evidence-based interventions.[13] An IS behaviour change framework, The COM-B wheel,[13] will be used to help analyse the findings of this study.

RESEARCH QUESTION AND OBJECTIVES

This literature review aims to answer the following research question: What strategies have been used to implement NHF therapy for infants (0-24 months) with bronchiolitis in rural and remote settings?

The objectives of this review are: a) to identify strategies important for the implementation of NHF therapy for infants with bronchiolitis, in rural and remote hospitals; and b) map each strategy to the COM-B wheel, an implementation framework. The findings will be used to inform the feasibility of implementing NHF therapy in rural and remote hospitals in North Queensland.

METHODS

An integrated review method, based on the framework by Cooper[14] and adapted by de Souza, da Silva and de Carvalho[15] was chosen as the best method to conduct this review. This is because an integrative review allowed for the inclusion of a diverse range of peer-reviewed sources, regardless of whether the methodology was qualitative, quantitative, or mixed methods. The authors also determined that the research question was not appropriate for a systematic review and meta-analysis.[16,17] As per the de Souza et al[15] framework, this review included six phases; formulating the research question; searching the literature; data collection; critical analysis of the studies; discussion of the results; and presentation of the integrative review. All phases were heavily influenced by IS as the overall framework that this review was guided by. The review was conducted by a remote area nurse with 20 years' experience (SW), and was supported by two nurse researchers (NH, SC) in regional and rural Queensland and a rural health clinician researcher (AC).

SEARCH STRATEGY (INFORMATION SOURCES)

A systematic search was conducted by one reviewer (SW) using CINAHL, PUBMED, MEDLINE, SCOPUS, INFORMIT, Cochrane Database, Joanna Briggs Institute and Google Scholar using the main keywords "Bronchiolitis" and "Nasal High Flow" and "Rural and Remote" on the date: 27.07.2021 (search strategy listed in Appendix B). When all three keywords were combined using Boolean terms "OR" and "AND" no results were produced. Therefore, the search was re-run removing the keywords "Rural and Remote", which then yielded 885 results. Google Scholar was searched using the keywords "bronchiolitis" and "nasal high flow" and the first five pages reviewed for missing studies. Manual searching of reference lists for all included studies was conducted. Results were exported into Endnote (version X9, Clarivate Analytics, PA, USA)[18] and duplicates were removed. Due to the keywords "Rural and Remote" not yielding any results and the search having to be rerun without these terms the research question was amended to: "What strategies have been used to implement NHF therapy for infants (0-24 months) who have bronchiolitis". The objectives were also revised to remove the words 'rural and remote'.

STUDY SELECTION AND ELIGIBILITY CRITERIA

Two reviewers (SW & AC) independently conducted the title, abstract, and full text screening against the eligibility criteria (Table 1). Any discrepancies between the two reviewers were resolved through discussion. Infants were defined as children aged 0-24 months, excluding neonates. Bronchiolitis was defined by the diagnosis described within the publications. Implementation strategies were defined as processes or policies that were used to support the delivery of NHF therapy and were able to be transferable to the rural and remote context.

TABLE 1: ELIGIBILITY CRITERIA

Inclusion criteria	Exclusion criteria
Rural and remote context English language Infants with bronchiolitis Peer-reviewed Implementation strategies evident for example: • Clinical procedures • Training/education • Staffing ratios • Environment of care • Frequency of observations	Non-English language Non-bronchiolitis presentations Pre-term infants Not peer reviewed Grey literature Publications that made no reference to implementation factors Studies focused on invasive procedures Home oxygen

There were six categories identified from the preliminary review of the literature, These categories included clinical procedures: any procedure required to perform alongside the use of NHF therapy; staff ratio: what the ratio of patient to nursing/respiratory therapy staff was required; observations: regime of observations including frequency and type of observations included, for example recordings of oxygen saturations, pulse, respirations; medications: what medications were recommended; consultation: what timeframe and who was recommended/mandated to consult on the patient being placed on NHF therapy for example, paediatrician within two hours of being placed on the therapy; staff training: what was the minimum amount of training required, how it was delivered and for who and whether a competency in NHF therapy's use was required. All implementation factors were then coded against the six categories. Studies were excluded where NHF therapy was being used for invasive procedures such as intubation for anesthetic as this is not a routine indication for NHF use in the emergency rural and remote setting.

DATA CHARTING AND ANALYSIS

Study characteristics were charted collaboratively by two reviewers (SW & AC). Data extracted included lead author, publication year, purpose/aim, study design, setting (where provided), Mixed Methods Appraisal Tool (MMAT) score, key findings, and implementation factors. Using a reflective and iterative approach, implementation factors were only included if they could be applied to rural and remote settings. The implementation information was then grouped inductively into themes.

The COM-B wheel (Figure 1), an implementation science, behaviour change framework,[13] was used to help structure and analyse the publications that were identified during the study selection and eligibility criteria. Each implementation factor identified in the included studies was mapped onto the COM-B wheel and categorised into the three levels (1: system, 2: local context, 3: Individual); and also the three domains of behaviour change – capability, opportunity and motivation (Figure 3).[13] Level 1 represents an organisational/systemic/cultural influence, level 2 refers to the local setting where NHF is being implemented, and level 3 is at the individual level and refers to the frontline staff using NHF therapy.

CRITICAL APPRAISAL

Methodological quality was assessed independently using the MMAT[19] by two reviewers (SW & AC). Overall, four studies were categorised as being mixed methods, seven studies as being quantitative, three studies as being quantitative non-randomised, one study as being quantitative randomised controlled trial, and one paper was not able to be categorised due to the absence of a research question.[19] With respect to the quality appraisal of the 16 papers, six papers were graded as high, seven as moderate, two as low and the paper with no research question was unable to be graded. Despite this paper not having a research question, it did meet the eligibility criteria for inclusion and contained valuable information that helped address the research question. Any disagreements were resolved by discussion until consensus was achieved.

RESULTS

A total of 885 publications were identified. After removal of duplicates, the combined database searches yielded 750 peer-reviewed publications. After title, abstract and full text screening was undertaken, 734 publications were excluded, yielding a final sample of 16 eligible publications from 15 studies (Figure 2).[20-35] One study resulted in two publications.[25,30] As the search yielded no studies that were conducted in a rural and remote context, the research team recognised that metropolitan-based studies potentially held valuable knowledge on implementation that could be applied to the rural context.

SUMMARY OF OVERALL RESULTS

Table 2 presents characteristics of the 16 included publications (15 studies).[20-35] Most studies were based in America (*n* = 7),[20,22,24,28,32-34] three were from Australia,[21,26,27] three from South America (Brazil and Peru),[25,29,30] and one each from Egypt, Turkey, and Italy.2[3,31,35] Implementation characteristics from the included studies were mapped onto an adapted COM-B behaviour change wheel (Figure 3). Six publications identified implementation factors associated with capability,[20,23-25, 27,30] all 16 publications reported opportunity implementation factors,[20-35] and two identified factors associated with motivation.[25,28,30] The COM-B factors were stratified by categorising each implementation factor into three social levels and domains of behaviour change.

CAPABILITY

Staff training was identified in all three COM-B levels (Figure 3).[20,23-25,27,30,35] One study used a System level Knowledge to Action framework to provide a comprehensive approach in identifying barriers and enablers, for example, establishing regular interdisciplinary meetings.[25] Another system level

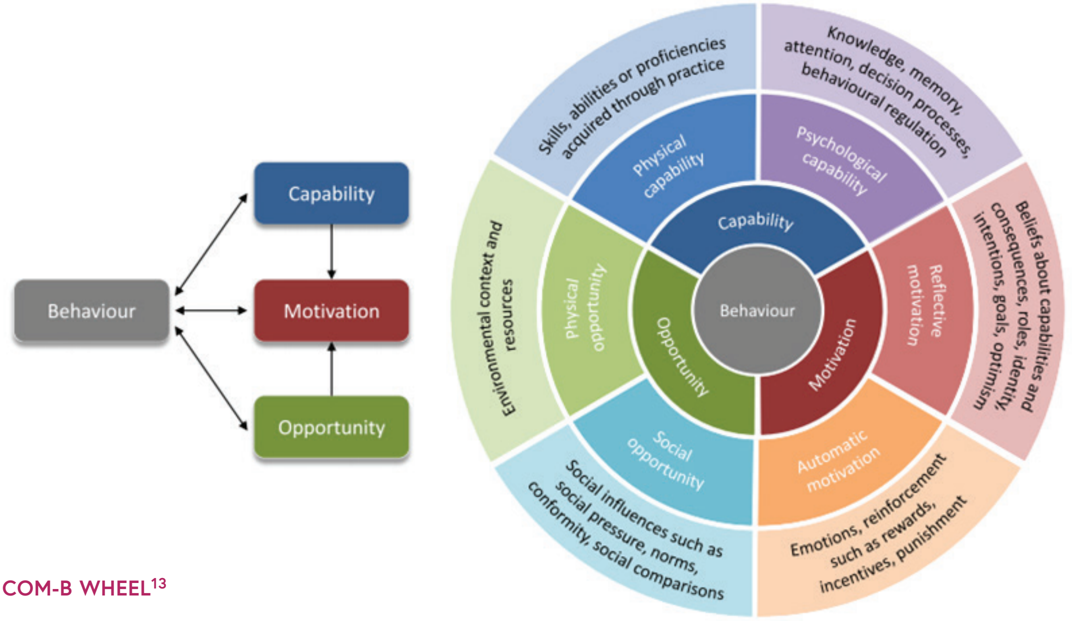

FIGURE 1: THE COM-B WHEEL[13]

TABLE 2: CHARACTERISTICS OF INCLUDED STUDIES USING NHF THERAPY WITH INFANTS DIAGNOSED WITH BRONCHIOLITIS

Author, year, country	COM-B level	Purpose/aim	Study design, setting (where provided)	MMAT Score (25)	Key findings	Implementation factor
Babl et al., 2020[21], Australia	1,2	Safety of enteral feeding in children <12 months on NHF therapy.	RCT	4	No adverse events when using enteral feeding while receiving NHF therapy. One child sustained a pneumothorax unrelated to the feeding.	Clinical procedures: feeding
Abboud et al., 2012[20], USA	1,2,3	Identify variables predicting NHF failure.	Retrospective chart audit	–	81.4% of children responded positively to NHF therapy., High pre NHF therapy partial pressure of carbon dioxide levels, lower respiratory rates and lower weight were predictors of NHF failure.	Clinical procedures: diagnostics management; medications; observation consultation; staff ratio
Yurtseven et al., 2019[35], Turkey	1,2	Comparison of 1L/kg/min and 2L/kg/min NHF rates in children < 24 months	RCT, Emergency Department	–	There was no significant difference between the two flow rates in reducing the risk of treatment failure. The 1L/kg/min flow rate provided reduced wean time.	Clinical procedures: feeding; diagnostics management; medication; observation; consultation; staff training
Sochet et al., 2017[34], USA	1,2	Determine incidence of aspiration and nutrition interruptions when enteral feeding on NHF.	Prospective, observational cohort stud	4	0.75% of children experienced respiratory aspiration and 9% of children experienced nutritional interruption due to tachypnoea. Oral nutrition was tolerated.	Clinical procedures: feeding
Slain et al., 2017[33], USA	2	Explore adverse feeding events and associations between enteral feeding patterns and clinical outcomes for children on NHF	Retrospective chart review. PICU		No association found between NHF therapy and adverse events with feeding.	Clinical procedures: feeding; diagnostics management; observations
Seliem & Sultan, 2017[31], Egypt	1,2	Evaluate if heliox improved gas exchange when delivered through high-flow nasal cannula (NHF therapy) in infants.	RCT	3	Provided recommendations of how to use NHF therapy and heliox, with imaging and a strict observation regime.	Clinical procedures: diagnostics; medication; observations
Nielsen et al., 2018[30], Peru	1,2,3	Implementation process evaluation of NHF therapy .	Implementation science: knowledge to action	–	Safely implemented NHF therapy in a PICU unit using implementation science knowledge to action framework.	Observations; consultation; staff ratios; training
Miller et al., 2018[28], USA	2,3	Explore NHF practice variation across five American clinical settings.	Quantitative survey	3	Minimal consensus of definitions around NHF.	Observations
Mayfield et al., 2014[27], Australia	1,2	Feasibility for an RCT assessing the safety and clinical impact of NHF therapy	Prospective pilot study Paediatric ward	5	Informed on guidelines for a larger RCT to be conducted including further assessment of financial implications of NHF therapy.	Observations; consultation; staff ratios; staff training
Betters et al., 2017[22], USA	1,2	Identify patient characteristics associated with NHF failure.	Retrospective chart review. Non-ICU setting	4	Predictors of a child's NHF treatment failure: having a cardiac comorbidity; unable to wean oxygen prior to intubation.	Clinical procedures: diagnostics; observations
Bressan et al., 2013[23], Italy	1,2	Feasibility of NHF therapy use in a paediatric ward.	Prospective cohort observational pilot study. Paediatric ward	2	Can safely use NHF therapy for infants with moderate to severe bronchiolitis in the ward setting. No cases of therapy interruptions or adverse events.	Clinical procedures: diagnostics; medications; observations; staff training
Ellington et al., 2019[25], Peru	1,2,3	Describe social institutional factors relevant to implementing NHF therapy	Qualitative study (focus groups, one-on-one semi-structured interviews). ICU	5	Knowledge to action framework identified an implementation strategy in a resource-limited setting. Recommended hands-on training for nurses with a requirement of more regular training intervals.	Staff ratio; staff training
Franklin et al., 2015[26], Australia and New Zealand	1,2	Comparing standard oxygen therapy to NHF therapy.	Non-blinded, multi-centre RCT. ED, Ward	4	Escalation criteria determined with observation regime.	Clinical procedures: feeding; diagnostics management; medications; observations; staff ratio
Nascimento et al., 2020[29], So Paulo, Brazil	2	Explore if nasogastric tube insertion is a predictor for NHF treatment failure.	Retrospective chart audit	3	Nasogastric tube use is a predictor for treatment failure.	Clinical procedures: feeding; observations
Shadman et al., 2019[32], USA	2	Explore if feeding exposure is associated with time to discharge.	Retrospective chart audit	5	Feeding during NHF therapy was associated with shorter time to discharge. Adverse events involving feeding were not associated with a feeding method.	Clinical procedures: feeding; diagnostics management
Dadlez et al., 2019[24], USA	1,2	Evaluate feasibility and safety of high flow nasal cannula outside of the ICU	Retrospective chart audit	4	NHF therapy is safe to use outside of an ICU setting if the patient has no pre-existing comorbidities prior to receiving treatment.	Clinical procedures: feeding; staff ratio; observation; staff training

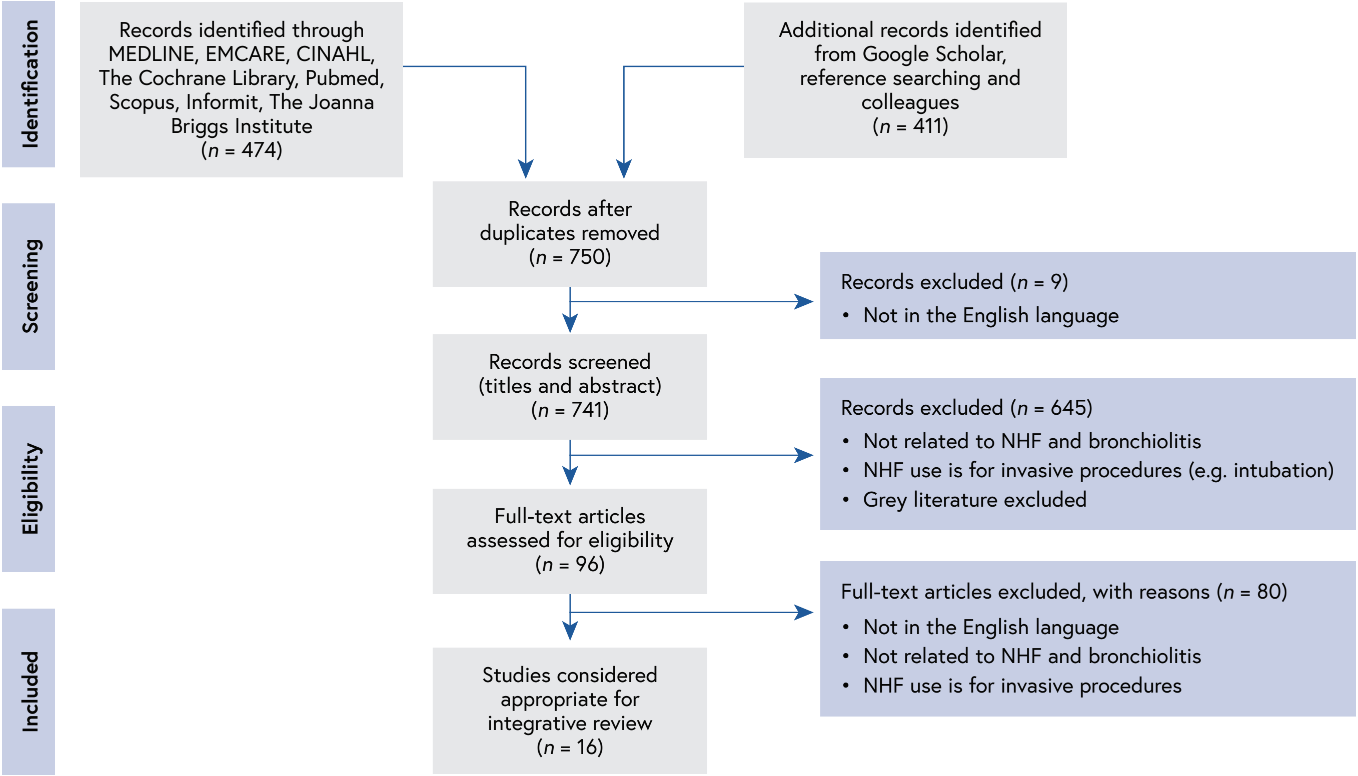

FIGURE 2: INTEGRATIVE REVIEW PRISMA FLOW CHART

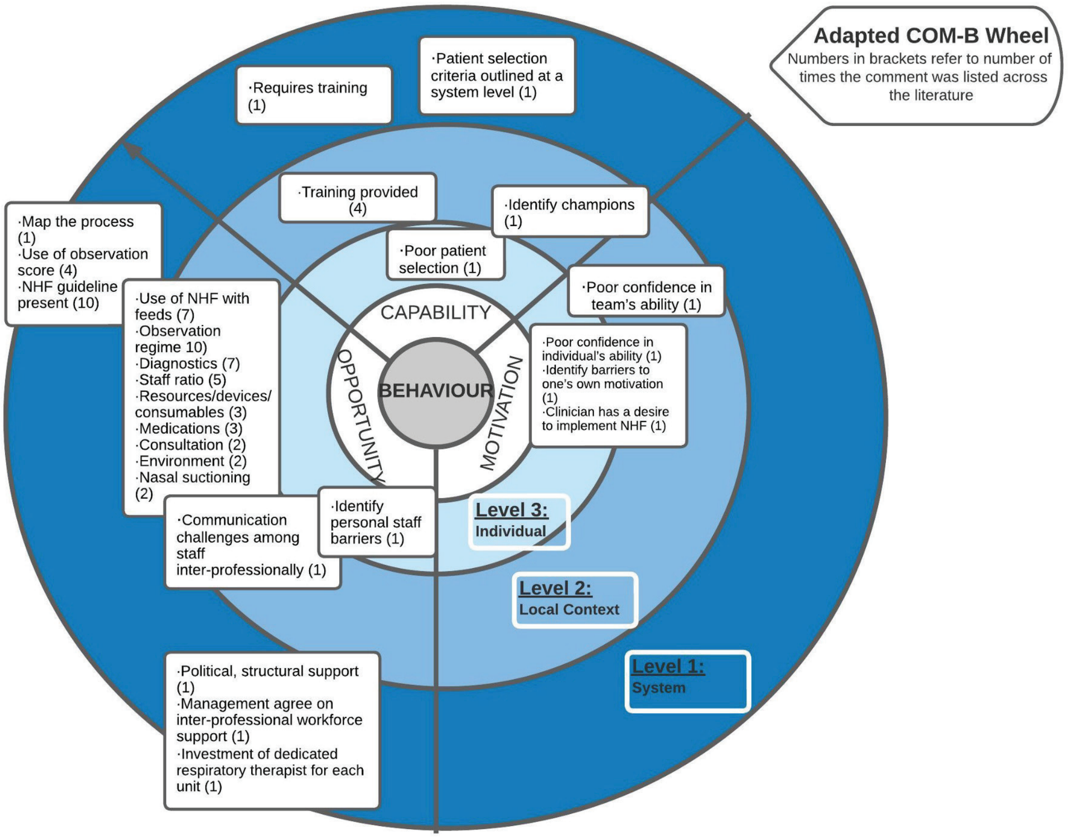

FIGURE 3: ADAPTED COM-B WHEEL WITH NHF THERAPY IMPLEMENTATION FACTORS MAPPED ON LEVELS AND INFLUENCING CAPABILITY, OPPORTUNITY, AND MOTIVATION DOMAINS

example is a pre-established patient selection criteria.[24] Four publications identified local context factors relating to implementing NHF therapy, including local champions to support staff knowledge transfer and mixed-mode training, tailored to different professional's needs.[23,24,27,30] At the individual level, the clinician's capability to identify patients appropriate for NHF, and a lack of training and knowledge in the use of NHF impacted on successful implementation of NHF therapy.[20] The clinician's poor confidence in their capability was reducing their likeliness of using NHF therapy.[20]

OPPORTUNITY

All three levels (system, local context, and individual) were represented in the *opportunity* category with all 16 publications describing an implementation process or factor that could be mapped to opportunity (Figure 3). The presence of a NHF therapy guideline[20-27,30,34] and the use of patient observation/respiratory tool were the two most commonly reported mechanisms to support implementation of NHF therapy.[20-31,34,35] The type of patient observation tool varied between studies and included: Work of Breath Observation Score,[20] Wood's Clinical Asthma Score,[29,31] a modified Bronchiolitis Severity Score,[23] the Child Early Warning Tool (CEWT)[26] and a Clinical Respiratory Score (CRS).[24,35] Organisational and managerial support at the **system-level** for the implementation of NHF was discussed in one study (two publications) as a change management strategy at the **local context** (unit) level.[25,30]

One study recognised individuals are key players in the implementation outcome and addressing any **individual level** barriers can reduce resistance to change.[30] Availability of resources and opportunities for staff to use NHF therapy was explicitly identified as a facilitator in two studies in relation to the treatment environment outside of the ICU setting.[20,22] The *opportunity* to use NHF was facilitated at a **local context** level by the existing clinical procedures around feeding, diagnostic processes, and medication use.[21,24,26,29,32-35] Eleven publications reported patient observation regimes.[20,22-24,26-29,31,33,35] These included: observing for treatment failure,[20,22,23,27,31,35] and a diversity of recommended observation regimes[24,26,28,29,31,33,35] including one study that implemented a specific respiratory therapist to observe NHF therapy patients for the unit.[28] These observation regimes are in addition to using the specific respiratory tools listed above.

Staff ratios provide an indication of workforce requirements and were reported in a third of the studies.[20,24-27,30] Ratios varied depending on the care environment and ranged from having a nurse:patient ratio of 1:2 (ICU)[30] to 1:4 (paediatric general ward).[20,26,27] Consulting with specialist doctors was reported in four publications, where the consultation was elicited in the emergency department.[20,27,30,35] Otherwise paediatric ICU consultants made the treatment decision to apply NHF therapy.[20,30]

MOTIVATION

Implementation factors that support the motivation of staff at both the individual and local context level were reported in two publications from the one study (Figure 3).[25,30] Key activities to support motivation included establishing local clinical champions, translation of the NHF therapy protocol onto large posters visible throughout the unit, and training that was tailored to the workplace needs. In this case the following model was considered to motivate the team to participate in the training: physician's training focused on the physiology of NHF therapy and nursing training focused on the practicalities of setting up and troubleshooting the NHF device.[30] There were no system level motivation factors identified.

DISCUSSION

The purpose of this integrative literature review was to identify factors relevant to the safe implementation of NHF therapy for the treatment of bronchiolitis in infants in rural and remote hospital settings in Australia. As most studies examined in this review did not include a description of implementation processes, limited information was gathered pertaining to the concept of interest. Importantly there were no studies that reported on the use of NHF therapy for bronchiolitis in rural or remote hospitals. Findings from this review will discuss implementation factors and strategies from metropolitan settings and consider how this can be applied in the rural and remote context.

NHF is a therapy used in emergency medicine and, like most treatments, is not without risk, including barotrauma.[36] Emerging evidence has refined the age-related recommendations for use of NHF therapy outlined by the Paediatric Research in Emergency Departments International Collaborative (PREDICT) guidelines and the Paediatric Acute Respiratory Interventions Studies (PARIS).[8,9,11,37] This integrative review does not consider efficacy of NHF against other treatments, acknowledging that in tertiary settings in Australia, NHF therapy is part of a standard complement of therapies available.

The two overarching predominant implementation factors identified by this review included staff capability and human resource support (i.e., staff knowledge and availability of specialist medical officers) and the physical resources to support the safe application of the therapy (e.g., NHF consumables and diagnostic equipment). While staff factors were represented across all three COM-B wheel domains and levels, staff training and staff ratios were reported most often. However, the compliance, duration, frequency, or mode of staff training was not reported. Educational enablers from both a system and local context level were reported including the adoption of local champions.[25,30] Rural and remote workforce challenges such as high staff turnover presents difficulties in maintaining a highly skilled but generalist workforce and strategies such as a 'champion' role, that can be handed over when staff turnover, should be considered during the early stages of implementation.[38] This implementation was used during the PARIS I and PARIS II trials resulting in a saturation of the intended knowledge within the workforce.[8,9]

There was a range of other human resource strategies used to support NHF implementation in the reviewed studies that are not available in rural and remote settings such as respiratory therapists and proximity to paediatric ICUs. The lack of these supports in rural and remote hospitals often leads to high nurse:patient ratio, which typically increase as rurality increases.[39] The standard hospital protocol for nurse:patient ratios of 1:4 is used in Australian tertiary emergency departments and paediatric wards.[26] Applying a nurse:patient ratio, derived from a specialised paediatric or tertiary ward setting would not necessarily consider additional logistical implications that exist in rural and remote communities.[4,40,41] This ratio would likely be insufficient in rural and/or remote Australia. Insufficient nursing staff was identified as a potential risk to more intensive care admissions with more invasive treatment and in rural and remote areas this often means aeromedical retrieval.[26]

Medical consultation was rarely discussed within the literature reviewed, and this appears to be due to the implied nature that consultation is continually occurring within the context of large tertiary and intensive care settings. However, Australian rural and remote communities, separated by large geographical distances, rely greatly on patients transferring to the tertiary hospital to access specialised medical care. Safe rural and/or remote health care depends on the ability to escalate care and time to access senior medical practitioner consultation.[22,42] The use of telehealth to address disparities in access to specialist services for rural and remote communities is growing and should be a consideration in all future service implementation processes.[43]

Resource constraints in rural and remote hospitals may limit timely availability of diagnostics such as pathology results and medical imaging. A locally conducted needs assessment, prior to the adoption of NHF therapy into routine practice, would be paramount to ensure adequate resources were available and pragmatic decisions around resource procurement could be conducted.[20,30] Also true to rural and remote Australian contexts, the acknowledgement of the local health context as well as political context within and external to the organisation were identified as paramount to success of an implementation study in the only NHF study reviewed that described an implementation strategy.[30] In this study, support from management for staff to practice in a more inter-disciplinary manner was considered an important enabler.[25] Rural and remote locations often have reduced staffing, which is multidisciplinary in nature. Therefore, there is a heavy reliance on inter-professional collaboration and training, which is a known supportive implementation strategy.[44]

Additional procedures such as enteral feeding while on NHF therapy may be a determining factor for inter-hospital transfers from a rural and/or remote context to a tertiary/specialist hospital. Severity of illness and early identification of treatment failure are essential considerations in managing emergencies in rural and remote hospitals, given the time considerations for accessing inter-hospital transfers, either by air or road. Some of the clinical findings reported in the reviewed studies provide salient information to detect early[22,42] treatment failure such as work of breath (including respiratory rate, oxygen saturations),[20,23,24,31] and timeframes for reassessment of the patients in facilitating early identification of deterioration.[20,31] Balancing the benefits of treating patients close to home versus the risk of patient deterioration is common place for rural and remote doctors and nurses and these staff make decisions based on a range of considerations, resources, patient presentation and confidence in the team's ability to safely implement care.[3,45,46]

The successful translation of new therapies such as NHF therapy into rural and remote contexts can be supported by the application of research translation theories and frameworks. Of note, only one study (2 publications) identified in this review explicitly described a structured implementation strategy.[25,30] The use of the COM-B wheel[13] in this review has highlighted where the gaps in current implementation processes (most notably in motivation) have been. The minimal motivation information still provided an understanding that an individual's confidence, across all contexts, can impact on whether an intervention will be taken up into everyday clinical practice.[30] The influence of an individual's opinion of their team's abilities also impacts and again is not context dependent.[30] The COM-B wheel has been used in previous health services research to identify strategies to promote the use of evidence-based clinical practice.[47] It is possible that an increased likelihood of positive practice change will occur when strategies supporting implementation are broadly spread across all the domains of the wheel.[13,47]

Rural and remote Australian hospitals are highly conducive to using implementation science theories and frameworks, given the importance of contextual barriers and enablers that are unique to this setting.[13] Poor uptake of interventions in rural and remote locations could be explained by a lack of consideration to the unique needs of these sites, evidenced by the absence of literature found by this review. Historically, NHF therapy has not been approved due to the unknown risks of applying this intervention in a rural and remote location.[10] However, implementation science has shown that factors such as local champions, guidelines, use of observational data, and having locally tailored training and supportive approaches does improve the implementation and uptake of NHF therapy.[24,25,26,27,30] The authors recommend these strategies be applied in rural and remote contexts to inform policies and procedures that will promote and support clinicians' capability, opportunities, and motivation to implement NHF therapy.

STRENGTHS AND LIMITATIONS

This review was limited to publications published in English. Relevant publications in other languages may have been missed; however, a broad range of databases were searched, and reference lists of included publications were searched. The search strategy followed an integrative review approach and did not include grey literature, excluding hospital guidelines and procedural documents. The lack of rural and remote specific studies limits our ability to translate the identified implementation factors into a rural context and arguably grey literature may have provided some insight into this. The quality appraisal of publications using the MMAT tool was found to be subjective and frequently required discussions between authors.[19]

This review informs on a peer-reviewed information gap around the use of NHF therapy in the rural and remote context. This review is translatable to inform clinicians on what information is available on how NHF therapy has been implemented in the past to inform on future guideline development.

CONCLUSION

This integrative literature review has shown the absence of peer-reviewed publications reporting on the implementation of NHF therapy for infants with bronchiolitis within rural or remote hospital settings. Implementation issues reported in the literature on the use of NHF with bronchiolitis in tertiary, metropolitan hospital settings is likely to have some applicability to the rural and remote context. Implementation of tertiary evidence to rural and remote settings requires a systematic understanding of implementation processes. Using the COM-B wheel to categorise the reported capability, opportunity and motivation of health systems, local departments, and individuals to implement a treatment such as NHF therapy in rural or remote settings highlighted the focus on the system level opportunity to deliver the therapy with minimal strategies to address motivation or capability.

Successful implementation of NHF therapy in rural and remote hospitals will require further research into associated risks and benefits for individuals and communities where emergency transfers for specialist care require considerable individual and health service resources. Careful consideration of the process for implementing NHF therapy will be important to ensure all behavioural change factors are addressed, potentially improving the safety and efficacy of the therapy. This is particularly important in the rural and remote context where the breadth of generalist skills required by staff in these settings and the lack of on-site respiratory or intensivist specialist skills creates challenges for maintaining important clinical skills.

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The primary author has accepted $5000.00 from Fisher & Paykell for the purposes of conducting NHF therapy clinical workshops with Torres & Cape Hospital and Health Service. Fisher & Paykell provided consumables to the value of $10 000 and Airvo2 devices to the value of $20 000 to Torres & Cape for facilitating research.

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CASE STUDIES

A nurse-led, telehealth transitional care intervention for people with multimorbidity: A feasibility study

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ABSTRACT

Objective: We aimed to develop and test the feasibility of a nurse-led, telehealth transitional care intervention for people with multimorbidity.

Design and methods: A feasibility study, using quantitative and qualitative methods was conducted at an 800-bed acute metropolitan hospital from March 2021 to January 2022. Eligible participants were adult in patients with multimorbidity. The intervention involved three stages: (1) baseline risk of readmission assessment and collaborative development of a Transition Action Plan; (2) transitional care coordination following hospital discharge, and (3) handover to the primary healthcare provider. A Transition Coordinator delivered the intervention with the aim of determining the intervention's feasibility in a practice environment. Acceptability to patients was assessed using a feedback survey. Acceptability to staff was noted through recorded interactions, collaboration, and feedback.

Results: Twenty-one adults with a mean age of 78 years participated in the intervention. Participants had 3-10 comorbid chronic conditions, and the most common were hypertension (71%), other cardiovascular (66%), renal (52%), and diabetes (47%). Most patients (52%) were at medium risk of readmission and 38% were at high risk, however, only 24% of patients were readmitted. The study identified there is no routine risk of re-admission screening for patients with multimorbidity, and the intervention was found to be acceptable and feasible to patients, ward staff, and the multidisciplinary team.

Conclusion: The results indicated feasibility of a transitional care intervention for people with multimorbidity, and the need for routine risk of readmission screening for people with multimorbidity. Further research is required to determine if the intervention is cost-effective and associated with reduced rates of hospital readmission.

Keywords: Care coordination, chronic disease, multimorbidity, nursing, telehealth, transitional care model

What is already known about the topic?

- People with multimorbidity often receive fragmented health services, which may increase their risk of hospital readmission.
- Internationally, Transitional Care Model interventions improve the transition experience from acute hospital care to the community and

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reduce short-term readmission rates, for people with multimorbidity.

- Transitional Care Model interventions have shown improved health and economic benefits for older adults. However, these benefits have not been evaluated in Australia.

What this paper adds

- This study provides evidence regarding the feasibility and acceptability of a low-cost, nurse-led, transitional care intervention to support people with multimorbidity transitioning from acute hospital care to home/community, in the Australian context.
- The study identified high support needs of participants upon transition and provides preliminary evidence in favour of a fundamental shift from discharge planning to stratified transition planning for patients with multimorbidity.
- Presently, on hospital admission, there is no systematic risk of readmission assessment or transition care planning and implementation for people with multimorbidity. This is a notable service gap requiring redress across South Australian Local Health Networks.

OBJECTIVE

This study aimed to develop and test the feasibility of a nurse-led, telephone transitional care intervention to support people with multimorbidity in their transition from hospital to the community.

BACKGROUND

Due to increasing life expectancy and improvements in healthcare, the prevalence of multimorbidity (i.e., the presence of 2 or more chronic conditions) is rising.[1,2] People with multimorbidity have health outcomes characterised by functional decline, decreased quality of life, and increased mortality.[3] Multimorbidity is costly for health systems and society, due to associations with high hospital readmission rates,[2] high healthcare utilisation,[4,5] and decreased productivity.[6-8] These challenges are perpetuated because health systems are designed for acute and critical illness episodes, and do not effectively address the needs of people with multimorbidity. This population often receive fragmented health services, leaving them vulnerable to receiving inadequate care at the point of transfer between the secondary and primary healthcare sectors, and at risk of preventable hospital readmission.

Evidence-based transitional care, a set of time-limited services provided during an episode of acute illness or symptom exacerbation between and across settings, is now a recognised approach to improve care for older adults by addressing some of these issues.[9] Systematic reviews have demonstrated that transitional care interventions decreased hospital readmission rates and associated health care costs among older adults and people with chronic illnesses.[10-12] Research indicates that successful transitions involve risk of readmission transition assessment and care planning, healthcare provider communication, preparation of the person and caregiver for transition, medication management, community-based follow-up, and patient education.[12-14]

The most rigorously tested set of transitional care interventions, the Transitional Care Model (TCM), has demonstrated enhanced health and economic outcomes for older adults with multimorbidity.[9,15] The TCM is a nurse-led intervention within a multidisciplinary team, targeting older adults at risk for poor outcomes, as they move across healthcare settings and between clinicians.[9,15] It emphasises identifying patients' health goals, designing and implementing a plan of care, and enhancing continuity of care across settings and between providers throughout episodes of acute illness.[9,15] Under this model, care is both delivered and coordinated by the same registered nurse in collaboration with patients, their caregivers, physicians, and other health team members. The focus is care coordination between the primary and secondary healthcare sectors.[9,15] Despite rigorous, multidisciplinary research supporting the TCM, it has not been tested for feasibility or adopted in Australia, further research targeting populations with multimorbidity in the Australian setting is warranted.[10-12]

The aim of this study was to develop and test the feasibility of a nurse-led, telephone transitional care intervention, based on the key components of the TCM, to support patients with multimorbidity in their transition from hospital to the community. Given that the intervention involves a new model of care, it is necessary to determine its feasibility and acceptability, as well as potential barriers to implementation, within the Australian context prior to conducting a randomised controlled trial (RCT).

STUDY DESIGN AND METHODS

A feasibility study was conducted using both quantitative and qualitative methods to determine whether a full trial (pragmatic Randomised Controlled Trial [pRCT]) of the model of care would be feasible. Arain notes that feasibility studies are pieces of research, used to estimate important parameters that are needed to design a main study.[16] Thus, the parameters used to evaluate this study's feasibility were drawn from Proctor's Evaluation Framework for Implementation Outcomes, these included: feasibility, acceptability, fidelity, and sustainability.[17] The successful feasibility of this study would determine whether a pRCT would be pursued.

As this was a feasibility study, generalisability was not required, similarly, the power calculation was unnecessary, but the sample size was relevant to sufficiently evaluate the identified parameters.[16] Ethics approval was granted by the Central Adelaide Local Health Network Human Research Ethics Committee (CALHN HREC 13646).

POPULATION AND SETTING

The eligible population was adult in patients 18 years of age and over who fulfilled all inclusion criteria and did not meet any of the exclusion criteria (see Table 1). The setting was an 800-bed acute metropolitan hospital with recruitment occurring between March-July 2021 and participants were followed up until December 2021. The Transition Coordinator informed potential participants about the purpose and nature of the study, verbally and in writing, and obtained their written informed consent to participate.

OUTCOME MEASUREMENTS

Feasibility studies are not designed to measure the outcomes of interest; that is the purpose of the main study.[16] Therefore, to assess the feasibility or usefulness of this study, our aim was to evaluate the acceptability and other specified parameters of the study intervention, in the practice environment, according to Proctors framework.[17]

INTERVENTION DEVELOPMENT AND MEASUREMENT

The study team, which included researchers and clinicians experienced in the care of patients with multimorbidity, developed the intervention. The intervention components were informed by evidence from the literature, particularly the Transitional Care Model (TCM), the team's prior experience in developing and testing models of care for people with multimorbidity, and the Stokes' Foundations Framework for developing and reporting models of care for multimorbidity.[12,18-21] The intervention, involved three stages, included elements aligned to Stokes' Foundations Framework and was provided by a registered nurse (Transition Coordinator [TC]). The TC was central to providing care coordination as a key aspect of the intervention. The details of the care coordination intervention are discussed below.

BASELINE RISK OF READMISSION ASSESSMENT AND PLANNING

The TC assessed participants at baseline to identify risk of readmission and needs upon transition. Areas of assessment included: frailty, activities of daily living, cognitive function, depression and anxiety symptoms, mobility, health literacy, medication management, comorbidities, nutrition, and end-of-life planning. Based on the assessment, the Transition Coordinator developed a Transition Action Plan (TAP) with the patient, which identified support services required on discharge (e.g., home medicines review, meals assistance, psychology, physiotherapy, occupational therapy). The Transition Coordinator notified each participant's general practitioner (GP)/practice nurse of the individual's participation in the service and invited their input on the TAP.

TABLE 1: INCLUSION AND EXCLUSION CRITERIA

Inclusion criteria	Exclusion criteria
Adult (over 18 years) patients (ward or emergency department)	Patients living in or likely to be discharged to high level residential aged care facility
Sufficient cognitive function and English language skills to provide informed consent and complete assessments	Patients enrolled in a comprehensive management program on discharge
Ability to engage in telehealth	
A history of either diabetes with cardiovascular disease (two specific chronic illnesses), or comorbidity in at least three of the following illness domains: • Diabetes: type 1 or type 2 • Cardiovascular disease: symptomatic atherosclerotic disease (ischemic heart disease, cerebrovascular disease, peripheral vascular disease, symptomatic valvular heart disease or atrial fibrillation) • Chronic cardiac failure • Psychiatric illness including mood or anxiety disorders • Respiratory disease including chronic obstructive airways disease, asthma, or interstitial lung disease • Kidney disease resulting in chronic renal impairment with creatinine clearance _30 ml/min • Current active malignancy	Patients followed up through other local health network (LHN) services providing community outreach such as patients who are homeless
	Patients with a current history of illicit drug or alcohol dependence which may interfere with ability to engage with the program
	Patients with palliative intent and likely to have a life expectancy of less than 6 months
	Patients due for elective readmission within 2 weeks of current hospital discharge

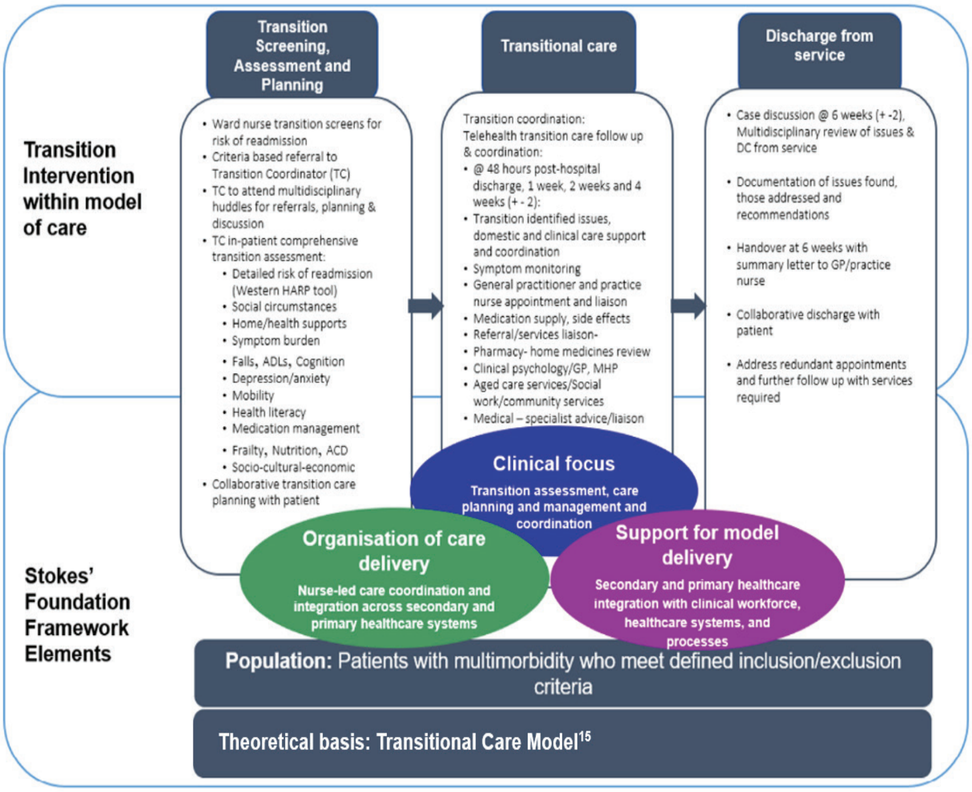

FIGURE 1. KEY COMPONENTS OF THE INTERVENTION, ALIGNED TO STOKES' FOUNDATIONS FRAMEWORK FOR DEVELOPING AND REPORTING MODELS OF CARE FOR MULTIMORBIDITY RISK OF READMISSION SCREENING, ASSESSMENT, AND PLANNING

The TC used the Western Hospital Admission Risk Profile (HARP) Risk Calculator to assess participants' risk of re-hospitalisation.22 This tool classifies risk of hospital readmission in the next 12 months as low, medium, high, or urgent based on presenting clinical symptoms, service access profile, self-management, and psychosocial issues.22 The TC also assigned participants a complexity score of low, medium, or high. Low complexity was defined as stable and self-managed multimorbidity with strong social support systems. Medium complexity was defined by socioeconomic or cultural factors, mental illness, and/or high symptom complexity without exacerbation. High complexity was defined by poorly managed multimorbidity, polypharmacy, socioeconomic or cultural factors, mental illness, and/or symptom exacerbation or instability.

TRANSITIONAL CARE COORDINATION

Following discharge, the TC provided transition coordination via telephone for 6-10 weeks, as indicated by patients' clinical stability. The first therapeutic telephone consultation between the TC and the patient or their significant other occurred within 48 hours of discharge from the hospital. This was identified as a vulnerable period for the patient by the Transition Coordinator and is consistent with previous literature.11 Subsequent phone calls were at weeks one and three from discharge, then fortnightly until the patient was stable or could be handed over to the GP/practice nurse (between six and ten weeks). During telephone calls, the TC reviewed: the TAP, symptoms, appointments attended, medication management, and domestic and health services required/accessed. The TC then undertook appropriate actions (e.g., service referral or follow-up, patient education, liaison with healthcare providers). A multidisciplinary case discussion was held four to six weeks post-hospital discharge between the TC and clinical team.

HANDOVER TO PRIMARY HEALTHCARE

Six to ten weeks post-hospital discharge the TC held a final transition discharge telephone consultation with the patient. The TC also provided the patient's GP/practice nurse with a discharge handover and letter summarising the issues identified, actions taken, and recommendations for ongoing care.

DATA COLLECTION

Transition intervention

The TC documented key information about each patient's transition in a purpose-built data collection tool using Microsoft Excel. The data collection tool included variables for: age; gender; country of birth; living situation; comorbid conditions; number of GPs, specialists, and pharmacies visited in the past 12 months; weight; total scores on baseline assessment measures; date of discharge; number of transition issues identified; total services required and accessed; total patient, health professional, and service phone calls made; whether an advanced care directive was in place; whether a home medicines review had been performed; and total hospital readmissions. At each patient phone call, the Transition Coordinator recorded the patient's condition (improved, deteriorated, stable, unstable), symptoms present, appointments attended since last contact, medications, actions taken (e.g., contacted GP, practice nurse, pharmacist, or specialist), support services required, and reason for readmission (if applicable).

Study feasibility: patient, nursing, and multidisciplinary staff experience and acceptability

Acceptability is the perception among implementation stakeholders that a given intervention, service, or innovation is feasible; that is, acceptable, useful, or satisfactory.[17] Evaluation of the feasibility of an intervention should therefore focus on the end-user's experience. The intervention in this study included two end-user groups. The first group was the participants enrolled in the transition service, and the second group included the ward staff and multidisciplinary teams who provided their care.

Within three months of discharge from transitional care, participants completed a survey tool that assessed their experience and acceptability of the care (Assessment of Transition and Care Coordination Service Tool). The survey was developed from validated patient and health practitioner continuity of care tools and assessed patients' experiences and views of care coordination and the TC role.[23-25] The survey items developed for the purpose of the study were piloted within the research team. As an indicator of TC activity and cost, TC activity hours per patient were recorded.

Perceived acceptability of the intervention among the second group was determined informally, based on recorded observation of their collaboration and engagement with the TC.

DATA ANALYSIS

All data were entered from the data collection template into RedCAP (Research Electronic Data Capture), which is a secure web application for building and managing databases. From RedCAP, data were exported into IBM® SPSS® version 26.0, for data analysis. Due to the small sample size, descriptive analyses were performed only.

REPORTING

The study was reported using the 'the 'CONSORT' checklist for reporting a pilot or feasibility trial.[26,27]

RESULTS

STUDY PARTICIPATION

A total of 71 patients were screened for eligibility for the study, of which 21 were eligible and completed the intervention (see Figure 2).

PARTICIPANT CHARACTERISTICS

Participant characteristics are reported in Table 2. Most participants were female (67%), over 76 years of age (72%), and living alone (52%). Participants reported 3-10 comorbid chronic conditions, of which the most common were hypertension (71%), other cardiovascular (66%), renal (52%), and diabetes (47%). Most participants received a hospital readmission risk score of medium (52%) or high (38%).

INTERVENTION

Feasibility and acceptability

Twelve of the 21 participants (57%) completed the survey. Overall, a high level of perceived acceptability of transitional care and the TC role were present in the survey responses. All respondents (100%) agreed that the Transition Coordinator provided effective telephone follow-up to the additional support services required, and 67% agreed that the services needed would not have otherwise been accessed.

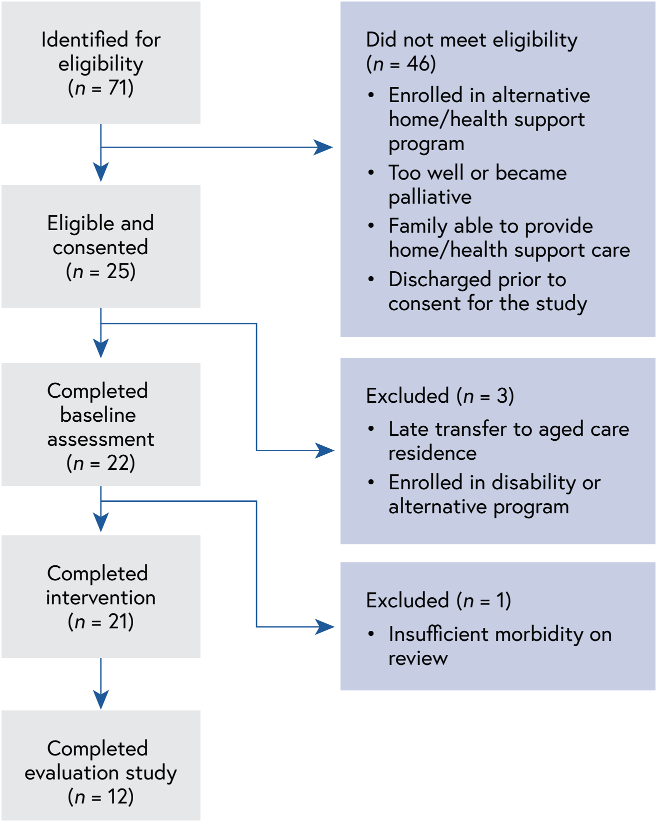

FIGURE 2. STUDY FLOW

TABLE 2. PARTICIPANT CHARACTERISTICS (*N* = 21)

Variable		n (%)
Gender	Male	7 (33)
	Female	14 (67)
Age	46-65	2 (10)
	55-75	4 (19)
	76-85	10 (48)
	86-95	4 (19)
	96-105	1 (5)
Living situation	Alone	11 (52)
	With partner	7 (33)
	With family or significant other(s)	3 (14)
Number of specialists seen in past 12 months	0	1 (5)
	1	4 (19)
	2	5 (24)
	3	4 (19)
	4	6 (29)
Number of chronic conditions	3-4	7 (33)
	5-6	8 (38)
	7-8	5 (24)
	9-10	1 (5)
Most common chronic conditions	Hypertension	15 (71)
	Other cardiovascular	14 (66)
	Renal	11 (52)
	Diabetes	10 (47)
	Hypercholesteremia	8 (38)
	Neurological	7 (33)
	Cardiac failure	7 (33)
	Metabolic/inflammatory	7 (33)
	Mental health	7 (33)
	Respiratory	4 (19)
	Pain	4 (19)
Hospital Admission Risk Profile	Low	2 (10)
	Medium	11 (52)
	High	8 (38)
Complexity	Low	2 (10)
	Medium	15 (71)
	High	4 (19)

Most respondents (92%) indicated that the Transition Coordinator effectively included family/significant others in accessing additional support services. Just over half (55%) of respondents felt the Transition Coordinator telephone conversations helped prevent a hospital readmission, and 50% agreed that they would have returned to the hospital emergency department if not contacted by the Transition Coordinator. Most (67%) respondents indicated a 6-week transitional follow-up was sufficient, however, one participant noted that allowing flexibility for a longer follow-up would benefit some individuals.

Regarding the acceptability of the technology used (telephone call), only 8% agreed they would prefer a video call, 41% indicated that they were comfortable with the technology, and 33% were unsure.

Perceived acceptability of the intervention by ward nurses, the multidisciplinary and medical teams were informally monitored and recorded as the intervention progressed. Ward nurses and the multidisciplinary and medical teams actively contacted and referred patients to the TC, included the TC in patient rounds, and discussed transition issues at multidisciplinary 'huddles'. For success and acceptability of the intervention, collaboration and cooperation with health practitioner groups was essential, and minimal barriers to collaboration were noted. The TC capitalised on organisational workflows (e.g., bed management meetings), and resources by providing information and receiving acceptability and feasibility feedback in the practice environment, through integrated meeting attendance, informal conversation, local ward signage and email.

Fidelity

The key aspects and general principles of the intervention were adhered to. However, based on the patients' clinical conditions, aspects of the intervention required minor adjustments. The first transition follow-up phone call was originally made after one week; however, this was adjusted to be made within 48 hours, due to clinical judgement that patient symptoms were too unstable to be unchecked for a week, unnecessarily exposing patients to the risk of readmission.

Flexibility was also required in the duration of the intervention, which varied from six to ten weeks. This was for several reasons. Firstly, the clinical judgement of the TC indicated that some patients were unstable and required continued monitoring. Secondly, the multidisciplinary meetings were not completely embedded to review patients for discharge. Lastly, although a process for general practitioner handover was described, it was not consistently implemented.

TABLE 3. TRANSITIONAL CARE SUPPORT SERVICES AND PHONE CALLS (*N* = 21)

Transition care elements		N (%)
Number of problems identified for Transition Action Plan	1-3	2 (10)
	4-6	4 (19)
	7-9	12 (57)
	10-11	3 (14)
Type of problem identified on Transition Action Plan	MAC/RDNS follow up	18 (85)
	Chronic Care Plan	16 (76)
	ACAT	14 (66)
	Pain	11 (52)
	Occupational Therapy	10 (47)
	Physiotherapy	9 (43)
	Medication dispensing follow up	9 (43)
	Vaccination	9 (43)
	Cardiac/fluid monitoring	9 (43)
	Respiratory/breathless	8 (38)
	Diabetes	8 (38)
	MRU/HITH	8 (38)
Number of support services identified for Transition Action Plan	1-4	1 (5)
	5-6	2 (10)
	7-8	4 (19)
	9-10	7 (33)
	>10	7 (33)
Types of home support services required	MAC	17 (81)
	ACAT	16 (76)
	Cleaning	10 (47)
	MRU	8 (38)
	Physiotherapy	8 (38)
	Occupational Therapy	8 (38)
Home medicine support	Pharmacist assessment and education	21(100)
	Home dispensing device used or needed	15 (71)
	Carer or other responsible for medications	4 (19)
	HMR performed	2 (10)

Transition care elements		N (%)
Number of services not accessed by end of transition period	0	12 (57)
	1	7 (33)
	2	2 (10)
Total readmissions within 28 days	0	16 (76)
	1	4 (19)
	2	1 (5)
Patient/significant other phone calls	3-4	9 (43)
	5-6	5 (24)
	7-8	4 (19)
	>8	3 (15)
Health practitioner phone calls	0	13 (62)
	1-2	6 (29)
	>2	2 (10)
Support service phone calls	0	11 (52)
	1-2	8 (38)
	>2	2 (10)
Advanced care directive in place prior to enrolment	Yes	9 (43)
	No and discussed with Transition Coordinator for action	12 (57)
Condition at first phone call	Improved	10 (48)
	Stable	5 (24)
	Unstable	5 (24)
	Deteriorated	1 (5)
Condition at final phone call	Improved	10 (48)
	Stable	8 (38)
	Unstable	2 (10)
	Deteriorated	1 (5)

Notes:

MAC – 'My Aged Care' aged care services provider. RDNS – Royal District Nursing Society

ACAT – 'Aged Care Assessment Team', specialised service team performing functional and cognitive assessment for the purposes of recommending in-home support services

HMR – home medicines review

MRU – Metropolitan Referral Unit. Provide assessment for short-term services such as blood glucose monitoring assistance, medication administration or activities of daily living assistance.

HITH – Hospital in the home, similar to MRU but provides longer term services.

Sustainability

Minimal barriers to implementing transitional care were evident, with early ward adoption enabling smooth service integration, indicating possible service sustainability. Staff actively contacted the TC, included the TC in patient rounds, and discussed transition issues at huddles. Due to the short duration of the trial, patient recruitment into transitional care was achieved through daily matching of patient criteria with electronic admission data. However, ward nursing staff recommended a transitional workflow improvement by using the electronic service referral process for the future.

DISCUSSION

This feasibility study trialled an integrated outpatient transition care model for people with multimorbidity. Within this model, a Transition Coordinator facilitated the transition of participants from in patient hospital care into primary care. The key model components were a comprehensive risk of readmission assessment; the development of an individualised TAP; and the coordination of patient care and support services by a Transition Coordinator, via telephone consultations, over a six-to-ten-week period post-discharge. The evidence-based intervention supported the significance of continuity of care in empowering and enabling people to self-manage their chronic conditions.[20] Feasibility was supported by the integration of the TC into ward routines, staff interactions, and support for the TC. Positive patient responses indicated acceptability of the intervention.

Participants' stability fluctuated throughout the intervention, confirming that the sample was a highly complex and vulnerable group. Yet, over the course of the intervention the number of unstable patients decreased from 24% at the first phone call to 10% at the final phone call. This suggests that the transition intervention time of 6-10 weeks was adequate and that improvement in patients' conditions was achieved, a finding supported in previous studies.[28] A level of instability in individuals with multimorbidity is to be tolerated.[29]

Transitional care demonstrated acceptability of workforce and system integration from a staff perspective, as evidenced by referral processes, clinical rounds, huddles, and collaboration. The transitional care intervention also demonstrated acceptability by utility of the HARP assessment in forecasting which patients required more support. Lastly, participants demonstrated acceptability of transitional care as indicated by high levels of agreement in survey responses regarding the value of transitional care coordination.[28] However, patients were at times readmitted without firstly advising the TC of their unwellness or deterioration, unfortunately, precluding early support to address symptoms deteriorating. This barrier to avoiding hospital admission requires further investigation and action in future studies. Other barriers to implementation included inconsistency of multidisciplinary discharge meetings and general practitioner handover. Yet, collectively, the findings point to the acceptability and feasibility of a Transition Coordinator working within a transitional care model, collaborating with ward nursing staff, medical teams, and allied health, and integrating routine readmission risk assessment into transition planning for patients with multimorbidity.

Participants deemed at greater risk of readmission based on their HARP risk score required more transition support, communication, and resources, as indicated by higher numbers of support service referrals, patient and health provider telephone calls, and Transition Coordinator nursing hours.[22] These results indicate that hospital readmission risk assessment can inform the provision of individualised support to patients with multimorbidity during transition, via the use of a TAP and regular communication with primary healthcare services. This is consistent with literature suggesting that transition interventions require adaptation to individual levels of independence and multimorbidity. For example, a 2018 study of transitional programs for people with diabetes, which included people with multimorbidity, reported that individuals with higher needs required higher home care support.[30]

Participants with more symptoms required more care coordination support. The relevance of symptoms in people with multimorbidity to clinical management and transitional support cannot be underestimated. Eckerblad's descriptive study found that patients employ a range of strategies, daily, to manage their multimorbidity symptoms, and that healthcare professionals can support these people by providing guidance on symptom management.[31] Tripp-Reimer's integrative review on symptom science and multimorbidity suggested that the interactions between condition, symptoms, and treatment require clear documentation, tracking, and management to support clinical care and outcomes.[32] Our findings suggested a link between patient symptoms, complexity, and readmission risk, although the sample size was too small for statistical analysis of this association.

The participants in this study were highly comorbid and all at risk of readmission. Presently, there is no risk of readmission assessment or transitional support service embedded within routine care to address their needs. This study implemented routine risk of readmission assessment, development of the TAP, and concurrent identification of support services required. This was a practical intervention that addressed an important gap in the transition care needs of people with multimorbidity by simply linking the patient to community services and enabling rapid access to specialist services if needed. Our findings indicate the intervention could potentially be implemented across many services given its feasibility and acceptability. Although the intervention could also be considered low-cost because it leverages existing services, cost-effectiveness needs to be determined.

A strength of the study was its use of theory to guide the research process, including Stokes' multimorbidity framework to guide the intervention development and Proctor's framework to inform evaluation of implementation outcomes. Additionally, as far as we are aware, interventions based on the TCM have not been trialled in Australia. Fidelity of the intervention was necessarily balanced with flexibility to ensure pragmatism and relevance to real-world clinical practice, thereby enabling home and hospital settings to provide realistic and increased reliability for clinical outcomes. There were also several study limitations that require consideration. The setting was a single large acute hospital, the sample size was small, and the design omitted the use of comparator groups; all of which indicate the findings cannot be generalised. Additionally, due to the small size of the study we were unable to include people with cognitive impairment. As this is a growing issue in society and healthcare, future research needs to include this population cohort. Notwithstanding these limitations, this study achieved its primary aim which was to test a transition care intervention for applicability and feasibility for routine clinical practice. The results indicate that a larger randomised controlled study, in which the intervention can be more rigorously tested and compared is warranted.

CONCLUSION

This study examined the feasibility of a telephone transitional care intervention for people with multimorbidity, a service not yet embedded within the local health network setting. The trial demonstrated acceptability, feasibility, fidelity, and sustainability: in essence, usefulness for patients and staff. Our findings suggested a link between patient symptoms, complexity, and readmission risk, although the sample size was too small for statistical analysis of this association, it merits further investigation. There is currently no process within the local health network to systematically assess risk of hospital readmission upon discharge, despite readmission in patients with multimorbidity being costly and possibly preventable. This study provided preliminary evidence to support a fundamental shift from discharge planning to transition planning for people with multimorbidity. Having identified the nursing hours required for a transitional care intervention, the acute care organisation and local health network are positioned to further trial a transitional care service and workforce model. Further research is required to determine if the intervention is cost-effective and associated with reduced rates of hospital readmission.

IMPLICATIONS FOR RESEARCH, POLICY AND PRACTICE

This study emphasises the importance of incorporating local contextualised evidence into both clinical practice and research. It showcases the potential benefits of a nurse-led transitional care approach in supporting individuals with multimorbidity as they move from hospital to community settings. This approach not only offers a potentially cost-effective solution but also enhances the continuity of care between acute and primary care settings.

A notable gap exists in the current admission process across the South Australian Local Health Networks, where there is no risk of readmission assessment for people with multimorbidity. The findings of this study underscore the urgency to further investigate transitional interventions to address this gap. Participants in the study demonstrated significant support needs during the transition period, suggesting a crucial shift is needed from traditional discharge planning to more tailored transition planning for people with multimorbidity.

Recommendations include implementing a pragmatic randomised controlled trial using an evidence-based TCM. This would quantify any association between TCM, decreased readmission rates and improved quality of life for people with multimorbidity, in the Australian context. While this model has been well-validated and supported in existing literature, its effectiveness within the Australian healthcare system remains untested.

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